

Contents

From the Operating Director's Desk		
Young Investigator Grants Program		
Foundation Initiatives	6	
Meeting Highlights/Announcements	7	
Patient Information	14	
Patient Forums/Support Groups	17	
Share Your Stories	18	
Drug News	19	
Patient Registries and Referrals	21	
MDS Centers of Excellence		
Information on Clinical Trials	24	
Educational Resources	28	
Foundation Publications	31	
Contributions to the Foundation	32	
In Memorium	33	
General Information	40	



From the Guest Editor's Desk

9th International Symposium on Myelodysplastic Syndromes: An Overview



Valeria Santini, MD
Associate Professor
of Hematology
University of Florence
Firenze, Italy

Florence, Italy: May 16-19, 2007

The approval of drugs "specific" for myelodysplastic syndromes and the recent acquisitions in terms of pathophysiology prompted renewed interest for this group of diseases. Thus, in a climate of novel therapeutical options and improved diagnostics, the Ninth International Symposium on Myelodysplastic Syndromes took place in Florence, last May.

The attendees were 1450, from 62 countries around the world, making Florence meeting the most crowded of the Symposia held until now and dedicated to Myelodysplastic Syndromes. This enthusiastic attendance was well reflected by the fact that the Auditorium and all the Sessions were well populated by hematologists who animated lively discussions and raised burning questions. Of course this energetic participation was driven by the possibility of applying new therapeutical agents and by the consequent need to focus the exact clinical targets.

For the first time, an International Nurse Forum preceded the Symposium, on May 15th. The Forum "A New Chapter in MDS: Turning the Page from Hopelessness to Hope" included contributions from physicians and nurses and was addressed to introduce the complexity of myelodysplastic syndromes to nurses, but also to discuss the practical aspects of

administration of new drugs, as well as to reflect upon the special relationship among MDS patients and attending nurses. We look forward to the Second Nurse Forum in 2009!!

During the 9th International Symposium on Myelodysplastic Syndromes chaired by Mario Cazzola, there were only 39 invited lectures in the plenary sessions, while an ample space was dedicated to oral selected communications (32) and posters (160), to allow a large number of attendees to present their data.

During the Opening Session, chaired by P. Greenberg and M. Tomonaga, three lectures updated on epidemiology, diagnostic classification and cytogenetics of myelodysplastic syndromes. These outstanding lectures set the pace for the quality of the entire Symposium. The Susanne Fleishman Memorial Lecture introduced by John Bennett, closed the opening session, with T.E. Quill, interest specializing in palliative care, addressing the important topic of decision sharing and communicating with MDS patients.

Another novelty of the Florence Symposium was the "Tito Bastianello" Award, instituted by Mrs. Francesca Bastianello, in memory of her husband, affected by MDS, to promote and support research on MDS. Mrs. Bastianello awarded five young investigators who presented the best contributions to the Symposium. The day ended in the wonderful courtyard of Palazzo Pitti, where everybody enjoyed Florentine food and wine.

The first day of the Symposium was dedicated to the pathophysiological aspects and interesting data have been presented

regarding gene expression signatures in different MDS subtypes, with particular regard to 5q- syndrome, as well as molecular and immune defects, alterations in signal transduction and the very much needed MDS animal models. Later on during the day, clinical results and perspectives in the use of azacitidine and lenalidomide were the subject of two minisymposia. Azacitidine associations with histone deacetylase inhibitors, anti CD33 antibody and thalidomide have been discussed, both from the biological and from the clinical point of view. Setting up optimal drug association and optimal scheduling should help us acquire better results in MDS treatment, and, in the case of azacitidine plus histone deacetylase inhibitors, if preliminary results from G. Garcia Manero are confirmed, it should become standard therapy.

For lenalidomide, its outstanding activity in 5q- syndrome was strongly confirmed with new data, but G. Mufti developed the issue of this specificity, while A. List and A. Giagounidis clarified the best theoretical and practical management of lenalidomide in the treatment of MDS with 5q- isolated or combined to other anomalies. Lenalidomide possible significant activity in non 5q- MDS was also matter of debate. Simultaneous sessions were centered on immunological pattern and anomalies in MDS and on the involvement of mesenchimal and dendritic cells in these pathologies.

On May 17th, the Symposium opened with three lectures in which other myeloid neoplasms than MDS were considered as model to help our understanding of molecular and biological mechanisms at the basis of altered haematopoiesis (PNH, MPD, and AML). The day then went on with a stimulating revision of diagnostics in myelodysplastic syndromes, in a dedicated plenary session and extremely energetic simultaneous sessions. The need for supplementary diagnostic tools morphology, like flow cytometry analysis, molecular markers detection identification of possible new prognostic

tools was the matter of a rich debate. In particular, L. Malcovati confronted the audience with the new WPSS prognostic scoring system, in which transfusion need in the course of MDS is considered a prognostic parameter. Following this line, the impact of iron overload in the natural history of transfusion dependent MDS was thoroughly analyzed in a mini-symposium and in a number of posters. The importance of iron chelation and of appropriate targeting of patients suitable for iron chelation was presented by N. Gatterman. The existence of a recently approved oral iron chelator makes extremely actual this previously neglected issue in the management of MDS.

To end, three sharp lectures updated on growth factors background (R. Invernizzi) and practical use in the treatment of MDS: E. Hellström-Lindberg clarified the optimal management of erythropoietin plus granulocyte colony stimulating factor, while D. Bowen discussed new ways to approach neutropenia and especially thrombocytopenia, with the new agent AMG 531.

On Saturday, May 19th, in a still crowded Auditorium, the evidence-based hematology regarding myelodysplastic syndromes was presented. This was an original style to conclude the Symposium and summarize the data of last years research and of clinical results.

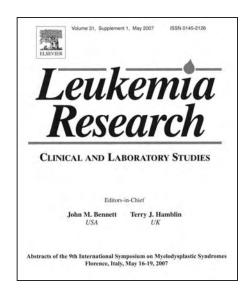
The different profiles of the ideal MDS patients candidate to be best responders to each of the therapeutical options available at present were discussed: growth factors, chemotherapy both low and high dose, the so-called epigenetic therapies: demethylating agents and histone deacetylase inhibitors, and bone marrow transplantation. The lectures of the day were meant to provide a sort of practical, reasoned "passé partout" to MDS treatment, which T. de Witte lively concluded.

After the closure of the Ninth Symposium, Saturday afternoon, MDS patients gathered in Palazzo dei Congressi, for an intense Patient Forum, the first of its kind in Italy, generously animated by a "not jet exhausted" Kathy Heptinstall.

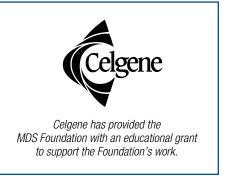
Florence was graciously hosting The Ninth International Symposium on Myelo-dysplastic Syndromes, offering to all attendees its best weather and all its art and beauty. The flying flags of the "sbandieratori" in Palazzo Corsini greeted with bright colors the attendees during the gathering for the social dinner: we hope to meet everybody again in Patras.

9th International Symposium

The abstracts of the 9th International Symposium on MDS published by Leukemia Research are now available upon request by contacting the MDS Foundation at 800-MDS-0839.



CD ROM from this symposium will be available soon.



From the Operating Director's Desk









Kathy Heptinstall Operating Director The MDS Foundation

This year has flown by! It seems that we were just starting 2007 yesterday and now we are once again in the throes of completing work on the functions that we will conduct during the ASH (American Society of Hematology) Annual meeting. Our Friday December 7th Friday Symposium—Changing the Characterization of MDS: Diagnosis to Therapy marks a decade of successful adjunct symposia at this important meeting. This meeting is chaired by Dr. Stephen Nimer of Memorial-Sloan Kettering in NYC and has a preeminent Faculty.

In addition to the Symposium we will again conduct a reception honoring the recipients of the 2007 Young Investigator Awards and we will be conducting our first "MDS Foundation Reception" at Turner Field in Atlanta. This will be an informative and fun evening on Sunday, December 9. If you would like to attend please contact us at the Foundation's Booth and *learn how to earn* your ticket.

The Foundation has continued to broaden our reach to patients and physicians in 2007. Two of the meetings are highlighted in this newsletter but these are only the tip of the iceberg! One of our staff members suggested that we look at *where in the world the booth has been* to make our MDS Foundation Booth and materials the 'Flat Stanley' of MDS education and information! So where have we gone to educate patients and healthcare providers about MDS?

During February and March we conducted Patient Forums in Freiburg, Germany; Seattle, Washington; and Duarte, California. These were highly successful and helpful to our many patients and support persons who attended them. Drs. Michael Lübbert, Joachim Deeg, and Mark Kirschbaum spoke to the patients and their caregivers about MDS and the hope that new treatments are bringing to patients.

In March 2007 the Foundation and our booth traveled to Punta del Este, Uruguay to

participate in the ISH meeting for Latin and South America. The response of physicians from these countries was astounding! We provided information in English, Spanish, Portuguese, and even Japanese to attendees! At the end of the first day there was literally nothing left of the thousands of pieces of information we took to this meeting.

We conducted our first nursing symposium at the Oncology Nursing Society's Annual Meeting in Las Vegas, Nevada to a standing room only audience. Serving as Faculty for this event were Sandy Curtin, Jeanne Ridgeway, Kathleen Weaver of the MDS Foundation, Lew Silverman, MD and Erin Demakos. Since then we have distributed hundreds of copies of this symposium on CD ROM to nurses worldwide.

The British Society of Hematology meeting in Bournemouth, England followed quickly. This marked our 4th year of participation in this UK-wide meeting. We moved to London from Bournemouth and conducted a Patient Forum for the UK MDS group. This forum will form the basis for a UK-wide Patient Support Group. Drs. Ghulam Mufti and Sally Killick provided information and answered questions for the attendees and their families.

For the fifth year we participated in the BIO 2007 Conference. This year it was held in Boston, Massachusetts. It is here that we make contact with companies conducting research in MDS and other patient advocacy groups from around the United States.

The 9th International Symposium on MDS was held in Florence, Italy on May 16–19 and attracted more than 1450 participants. Please read the editorial in this addition by Dr. Valeria Santini outlining the outstanding symposium. We congratulate Professor Mario Cazzola and his Scientific Committee on presenting what might be the best MDS meeting ever held! In addition to the full scientific meeting we conducted a Nursing Forum and a Patient Forum as adjunct meetings. Both were extremely well attended and greeted enthusiastically by the participants.

The American Society of Clinical Oncology (ASCO) was the next 'stop on the road' for our booth and information. This was once again a very successful meeting for distributing the Foundation's many educational and information pieces for patients and physicians. The interest in hematologic malignancies is growing every year in what was previously thought of as a solid tumor-oncology focused meeting. At the end of June we conducted a Patient Forum in conjunction with Mayo Clinic and Dr. David Steensma. This was a very well attended meeting that benefited these Minnesota patients and their families.

I had the privilege of participating in a meeting for hundreds of physicians from all over Russia to educate them on MDS, its diagnosis and new treatments and on the needs of patients living with MDS. This coincided with the approval of decitabine (Dacogen) in Russia. Our Patient Handbook and Iron Overload Handbook have now been translated into Russian for use by patients in this enormous country. The need for information was apparent in this group of physicians as evidenced by their active and attentive participation in both the plenary and breakout segments of this meeting.

We presented our third consecutive symposia as well as our booth and information at the European Hematology Association's Annual Meeting in Vienna, Austria. The well attended symposium and influx of visitors to our booth for information in the many languages of Europe make this a busy and extremely worthwhile meeting each year. We look forward to our participation in 2008!

We conducted patient forums in Baltimore, Maryland; Dubrovnik, Croatia, and Sinaia, Romania in September and October. In addition, during this time period the Foundation participated in the XXIII Symposium of the IACRLRD in Freiberg, Germany and the Leukemia/Lymphoma meeting in Dubrovnik. Please read the synopsis of these meetings written by our US Patient Liaison, Audrey Hassan.

We also presented the booth and materials to participants in the ISH-

European and African segment in Budapest, Hungary and to the ISEH Congress in Hamburg, Germany.

On September 28 and 29th the Foundation participated in the first MDS Symposium to be held in South America. The meeting was conducted in Fortaleza-Ceará, Brazil and was hosted by many of the Brazilian physicians we have come to know over the years including Drs. Luiz Fernando Lopes and Silvia Magalhães. More than 100 patients attended their Patient and Family Forum. The attendance at these meetings clearly demonstrates the needs that patients and families have for support and information everywhere in the world.

In late October, Jean Goasquen (Rennes, France) and John Bennett (our Chairman) conducted a "first of its kind meeting" in New Orleans, Louisiana for the American Society of Clinical Pathology. Attendees were provided with a new method of learning about MDS morphology through an innovative program called *Virtual Microscopy*. This was the inaugural session of a sixpart series on MDS Morphology which will allow hematopathologists and others who interpret MDS pathology as part of the intricate and important process of diagnosing and categorizing MDS patients to earn an Expert in MDS Morphology designation from the Foundation. Please read the announcement in this edition of the newsletter and join us online to participate in this important CME program.

Following that meeting, we held the initial gathering of the International Working Group on MDS Cytogenetics. We will keep you up to date as this group begins its important work focused on better defining cytogenetics in MDS!

Last month we attended the 4th International Congress on MPD and MDS in New York City, hosted by Dr. Richard T. Silver of Weill Medical College of Cornell University, New York, NY.

Now ASH is, as I noted at the beginning, here again. The Foundation has made, in 2007, great inroads into spreading the word about MDS, educating physicians

worldwide, engaging nurses worldwide in this process, and helping patients everywhere in living with MDS. 2008 is shaping up to be just as busy with events planned through ASH 2008 in San Francisco! These include some of the same events but also new ones. We are planning the next MDS Foundation Golf Tournament benefiting our *Young Investigator Grant Program* in Tampa, Florida on February 18. This tournament is a one fundraiser each year and is being conducted for the second year in conjunction with the H. Lee Moffitt Cancer Center in Tampa.

We will conduct our first satellite symposium at the European Oncology Nursing Society and will once again participate with the Groupe Français des Myélodysplasies in their biannual meeting. The Foundation also hopes to participate in the first National Update on MDS that will be held in July in Mumbai, India and has accepted the task of presenting a symposium on MDS during the ISH 32nd World Congress in Bangkok, Thailand.

In addition to these endeavors we are pleased to announce that we will hold our first US-wide and EU-wide Patient and Family Forums in early fall of 2008.

I would like to thank our supporters on behalf of the Foundation and its Board of Directors. These supporters, first and foremost, are the MDS patients, their families and friends, who form the core of this Foundation. You are our center and the reason that the Foundation exists. We work for you!

The second group that we would like to thank are the pharmaceutical companies that provide us with so much support and assistance. This assistance is given in the form of grants that fund programs that are non-product related but, rather, are geared toward improved disease knowledge and patient support. We could not do the work we do without this type of support.

From all of us at the Foundation, I wish you a wonderful Holiday Season and a Happy New Year!

MDS Young Investigator Grants Program

Foundation Awards Grants



THE YOUNG INVESTIGATOR GRANT PROGRAM FOR FELLOWS IN HEMATOLOGY

In December 2005 The Myelodysplastic Syndromes Foundation, Inc., initiated a series of grants "The Young Investigator's Grant Program for Fellows in Hematology". These awards are granted annually.

The Grant Review Committee selected Klas Raaschou-Jensen's grant submission entitled "Identification and Characterization of the Genetic Background in a Unique Danish Family with Several Cases of Hypoplastic Myelodysplastic Syndrome" and Azim Mohamedali's submission entitled "Prevalence and Pathogenetic Significance of Uniparental Disomy on Chromosome 4q in RARS" as the two Young Investigator Grant winners.

The 2008 Recipients Are:



Azim Mohamedali, PhD Kings College London London, United Kingdom



Klas Raaschou-Jensen, MD Copenhagen University Hospital, Rigshospitalet Copenhagen, Denmark

The Foundation is dedicated to furthering the research into MDS and invites Young Investigators (under the age of 40) to submit either basic or clinical research proposals into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis, or management of the Myelodysplastic Syndromes.

THE YOUNG INVESTIGATOR GRANT PROGRAM

is supported by this year's

MDS Foundation-H. Lee Moffitt Cancer Center Golf Tournament for MDS: February 18, 2008

Platinum Sponsors:

Silver Sponsor:







U NOVARTIS

Bronze Sponsors:

genzyme

The application deadline for 2009 grants is June 15.

Notification of the awards will occur by October 1, 2008 with activation on January 1, 2009.

NEXT YEAR'S TIME LINE

Proposals Due: Friday, August 15, 2008

Notification of Awards: Wednesday, October 1, 2008

Award Ceremony: Friday, December 5, 2008

Save the Date for the Second Annual MDS Foundation-H. Lee Moffitt Cancer Center Charity Golf Tournament for MDS

Presented by Bruce Fleisher (PGA Champions Tour Professional)



Myelodysplastic Syndromes Foundation— H. Lee Moffitt Cancer Center

CELEBRITY PRO-AM FOR MDS

VIP Gala: February 17, 2008 (open to non-golfers)

Golf Tournament: February 18, 2008

Innisbrook Resort & Golf Club Copperhead Course Tampa Bay, Florida

Sponsorship Opportunities Available
For more information please go to
www.mdsgolftournament.golfregistrations.com
or call 609-298-0342.

mds foundation

r. H. Lee Moffitt at the 2007 MDS Foundation-Moffit Concer Center Charity Golf Tournament for MDS





Clear your calendar... the date is set!

February 18th, 2008 will mark our 2nd Annual Charity Golf Tournament to be held at Innisbrook Golf Resort. You are cordially invited to be a part of the Gallery for this important charity event. The proceeds from this tournament will be donated to The

(continued on next page)

Young Investigator's Grant Fund for Fellows in Hematology that will provide resources to further the research of MDS and hopefully, to one day find a cure. Look for future announcements and invitations with more specific information as the time nears. And don't forget to practice!

Special events include:

- Celebrity Pairing Party—a chance to mix and mingle with the participating celebrities and PGA Champions Tour Professionals
- Clinic and Small Group Instruction with the Pros
- Awards Dinner and Live Auction (including fabulous golf packages with some of the top players on the Champions Tour!)

Interested players and sponsors are invited to contact the MDS Foundation at: 1-800-MDS-0839

Email: kweaver@mds-foundation.org or visit our golf website at www.mdsgolftournament. golfregistrations.com

MDS Essentials E-Newsletter

The Foundation has created a new electronic E-Newsletter to provide healthcare professionals and patients from around the world with timely information, in a cost-effective manner. The MDS Essentials E-Newsletter is the electronic version of our quarterly newsletter. Receive up-to-date information on clinical trials, research and news by simply subscribing online at:

www.mds-foundation.org.

Foundation Initiatives for 2008 and Beyond...

The MDS Foundation is committed to making a significant contribution to the advancement in understanding and of accurately diagnosing the myelodysplastic syndromes. We will be focusing our efforts in the following initiatives:

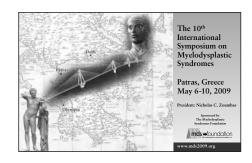
ADOPT REGISTRY



Sponsored by a grant from:

Qenzyme

- PATIENT QUALITY-OF-LIFE FORUMS
- WORLDWIDE PATIENT SUPPORT GROUPS
- 10TH INTERNATIONAL MDS SYMPOSIUM, PATRAS, GREECE: May 6-10, 2009



ADDITIONAL PROGRAMS

- Differentiating Anemia (CME Program)
- MDS Practice and Treatment Survey
- The International Working Group on MDS Morphology
- Transfusion Burden Registry
- The International Working Group on MDS Cytogenetics
- The International Working Group on Quality of Life in MDS

CME AWARENESS PROGRAM

Understanding MDS: A Primer for Practicing Clinicians

Visit www.mds-foundation.org and click on The MDS Foundation Resource Center to take advantage of this comprehensive program, and other informative programs coming soon, designed to provide you with tools and information that will assist you in administering the best care to your patients.

The first four segments of this eight segment series are currently available:

Segment 1: The Past & Present in MDS

Segment 2: Clinical Presentation,
Diagnosis & Pathology

Segment 3: Ineffective Hematopoiesis: Considerations in Diagnosis and Treatment

Segment 4: Anemia in MDS: Survival, QoL, and Treatment Options COMING SOON!

Written programs are available in Spanish, French, Italian, German and Japanese.

- CE Awareness Program for Nurses
- CE Awareness Program for Pharmacists

Sponsored by grants from:

















Pharmion has provided the MDS Foundation with an educational grant to support the Foundation's work.

Meeting Highlights and Announcements

MDS Mission for Nursing Education

Educational Symposia held in Las Vegas, Nevada and Florence, Italy

MDS Satellite Symposium held at the Oncology Nursing Society (ONS) 32nd Annual Congress

The MDS Foundation was pleased to participate in the ONS annual meeting held this year in Las Vegas where we presented the Foundation's first symposium in conjunction with ONS. Our Satellite Luncheon Symposium — Clinical, Communication, and Coping Knowledge: The Keys to Helping MDS Patients on Their Journey to Hopewas held on April 24th, 2007 at the Mandalay Bay. More than 300 nurses gathered for this meeting making the Foundation's first nursing adjunct symposium a great success. Our booth was extremely well attended and nursing colleagues from across the country joined us to learn more about MDS and their treatments.

Our distinguished faculty included Lewis Silverman, MD (Mt. Sinai Medical Center in New York City), Erin Demakos, RN, CCRC (Mt. Sinai Medical Center), Sandy Kurtin, RN, MS, AOCN, ANP-C (Arizona Cancer Center, Tucson), and Kathleen Weaver, Grant and Funding Director for the MDS Foundation. Topics included Managing MDS Patients: The Physician Perspective, Low-Intermediate 1 and High Risk Case Presentations, and What did we hear? What issues are patients/families dealing with? Information developed from the 28 Patient and Family Quality of Life Forums that have been held around the world formed the basis for this meeting.

For your free CD ROM containing all of the slide presentations from this symposium, please contact the MDS Foundation at 1-800-MDS-0839.

MDS CE Nursing Forum held at the 9th International Symposium on MDS

The CE Nursing Forum entitled *A New Chapter in MDS: Turning the Page from Hopelessness to Hope* was held immediately preceding the 9th International Symposium on MDS. At a five-hour symposium held on May 15th, 2007, the Presenters imparted information on improving communication with patients, allowing clinicians to better understand and appreciate the impact of an MDS diagnosis, the thought processes that physicians face in diagnosing MDS patients, conveying that diagnosis to patients and family members, and evaluating the impact of MDS specific management approaches and treatments.

FEATURED TOPICS AND FACULTY

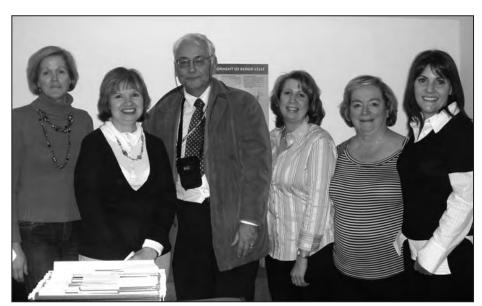
- An Update on Research into MDS Therapies
 David Bowen, MD
 The Leeds Teaching Hospitals, Leeds, UK
- Managing MDS Patients:
 The Nursing Perspective
 Erin P. Demakos, RN,
 Mt. Sinai School of Medicine, New York, NY

- Sandy Kurtin, RN University of Arizona Tucson, AR Jean Ridgeway, RN University of Chicago Medical Center Chicago, IL
- Essentials in Understanding:

 How Do We Determine Patient
 and Family Needs

 Barbara Deschler, MD

 University of Freiburg Medical Center
 Freiburg, Germany
- The MDS Foundation and the Journey to Hope
 Kathy Heptinstall, RN
 The MDS Foundation
 Crosswicks, NJ
- Managing MDS: Current Strategies and Standards Valeria Santini, MD University of Florence Florence, Italy
- What are the Myelodysplastic Syndromes: Understand a Difficult Disease Norbert Vey, MD Institut Paoli-Calmettes Marseille, France



Dr. Radu Gologan from Fundeni Clinical Insitute, Bucharest, Romania makes a visit to the MDS Foundation office in Crosswicks, New Jersey on November 8th.

The XXIII Symposium of the International Association for Comparative Research on Leukemia and Related Diseases

September 7–11, 2007 Freiburg, Germany

From Molecular Pathogenesis to Targeted Therapy in Leukemia and Solid Tumors

The 23rd Symposium of the International Association for Comparative Research on Leukemia and Related Diseases (IACRLRD) was held September 7-11, 2007 in Freiburg, Germany. This is the oldest international association and the meetings are held bi-annually. The venue was the University of Freiburg, Dr. Roland Mertelsmann the Symposium President. Roughly 300 participants consisting of internationally renowned physicians and research investigators along with young scientists attended the sessions which focused on the status quo and the future of targeted therapies. A summary of the program and other information is available at www.IACRLRD.de.

The strong scientific focus of the Meeting was the update on targeted therapies in myeloid leukemia, preleukemias including MDS and myeloproliferative syndromes, lymphoid malignancy and solid tumors. Numerous speakers presented exciting bench-to-bedside results on epigenetic therapy approaches both in MDS and in the biological and therapeutic continuum of high-risk MDS and acute myeloid leukemia, e.g. in older AML patients in whom intensive chemotherapy is not a meaningful option (reduced performance status, comorbidities etc.). The "targeted therapy" approach of the antiangiogenic agent lenalidomide in 5q- MDS patients provided a new and exciting paradigm for a rational therapy in a distinct MDS subtype based on a specific chromosomal aberration.

On Monday, September 10th the sessions on MDS were held. Chairs: N. Gattermann, Düsseldorf and M. Lübbert, Freiburg. Topics and faculty included:



The University of Freiburg served as the venue.

- H. Phillip Koeffler, USA:
 - From chromosomal losses to SNPs and epigenetic silencing: Molecular pathophysiology of MDS and myeloid leukemia
- Steven Gore, USA: Emerging treatment options in high-risk MDS
- Aristoteles Giagounidis, Germany:
 Modulation of angiogenesis in MDS:
 Clinical results
- Jürgen Finke, Germany: Curing MDS— Allografting options anno 2007

Foundation members Drs. Elihu Estey, Houston, Texas; Mark Kirschbaum, Duarte, California; and Valeria Santini, Florence, Italy were presenters as well during the 5day sessions. Members of the Foundation were also well represented on the Scientific Committee:

- S. Amadori, Italy
- S. Gore, USA
- E. Hellström-Lindberg, Sweden
- H. P. Koeffler, USA
- B. Labar, Croatia
- C. Niemeyer, Germany
- S. Nimer, USA

- M. Sanz, Spain
- T. de Witte, Netherlands





Nancy Mrzijak and Audrey Hassan of the MDS Foundation.



Dr. H.P. Koeffler, USA during his presentation.



Chairmen: Drs. N. Gattermann, Dusseldorf and M. Lübbert, Freiburg.

Dr. Lübbert expressed his pleasure that the Foundation could participate. One of the highlights of the social program was a tour of the world's third largest winery, Badischer Winzerkeller (Breisach), complete with a wine tasting that was sponsored by a very grateful patient of Dr. Lübbert's.

Dr. Clara Bloomfield assumed the presidency of IACRLRD during the meeting. The next symposium, in 2009, will be held in Columbus, Ohio and hosted by The Ohio State University Comprehensive Cancer Center.

Future symposia highly recommended are the EBMT meeting to be held in Florence, Italy in March 2008. It is anticipated that 4000 will attend with one entire day dedicated to MDS patients. Kathy Heptinstall, Operating Director of the MDS Foundation, will serve as Co-chairman of this Patient and Family Day. Another is the joint Annual Meeting of the German, Austrian and Swiss Societies of Hematology and Oncology (DGHO, OGHO, SGMO), taking place in Vienna, Austria, in October 2008.



Social Program

Badischer Winzerkeller Winery (Breisach) Sponsored by MDS patient, Mr. Alfred Wagner, pictured above with MDSF staff members Nancy Mrzljak and Audrey Hassan; and Dr. Lübbert.



Dinner in the Black Forest.



Dr. Lübbert extending a warm welcome.



Dr. Bloomfield, IACRLRD President, toasting Dr. Lübbert.

Leukemia and Lymphoma Symposium

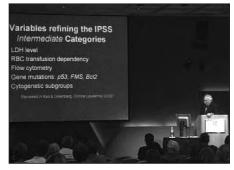
September 15–19, 2007 Dubrovnik, Croatia

East and West Together

A prestigious group of hematologists and experts in MDS attended this meeting. Drs. Cazzola, Cermak, de Witte, Greenberg, Hellström-Lindberg, Hoelzer, List, and Malcovati from the MDS Foundation were among this group.

On Sunday, September 16th the sessions on MDS were held. Chairs: P.L. Greenberg, USA; T. de Witte, The Netherlands. Topics and faculty included:

- P.L. Greenberg, USA:
 Classifications of myelodysplastic syndromes: recent advances
- L. Malcovati, Italy: Transfusion dependence and iron overload and prognostic modeling of MDS
- E. Hellström-Lindberg, Sweden: Low-risk MDS—do we need more than supportive care?
- M. Lübbert, Germany:
 Epigenetic therapy in the biological continuum of MDS and AML
- T. de Witte, The Netherlands:
 Stem cell transplantation (SCT) for MDS
- A.F. List, USA: New therapeutics for myelodysplastic syndromes
- M. Mistrik, Slovakia: Myelodysplastic syndromes management in Slovakia



Dr. Peter Greenberg from Stanford University one of the presenters in Dubrovnik who also serves as a member of the Foundation's Board of Directors.

(continued on next page)



Patients and Caregivers learning about the latest treatment options in MDS.



(L to R) Nancy Mrzljak (MDSF), Kim List, Dr. Alan List (MDSF Board of Directors), Dr. Boris Labar, and Audrey Hassan (MDSF).

Our patient forums continued in Europe with the Foundation's first patient forum held in Croatia on September 13th. Our speakers included Prof. Drs. Ranka Serventi-Seiwerth,



Dr. Sandra Bâsić-Kinda at the MDS Patient Forum in Dubrovnik, September 13th, 2007.



Gala Dinner in the Old Town.

Drago Batinić, and Sandra Bâsić-Kinda. The forum was conducted in conjunction with the Croatian Association of Leukemia and Lymphoma Patients.



MDSF staff members Nancy Mrzljak and Audrey Hassan.

Virtual Microscopy in MDS-AML: The Key to Enhancing Classification

October 18, 2007 New Orleans, Louisiana

Dr. John Bennett of the University of Rochester Cancer Center in New York along with Dr. Jean Goasquen of the Universite de Rennes in France presented a didactic course with hands-on participation in a virtual microscopy identification of MDS morphology program held in conjunction with the American Society for Clinical Pathology (ASCP) Annual Meeting in New Orleans. This program is the first of a CMEseries on MDS morphology presented by the MDS Foundation. Information on the goals and development of this initiative, the developmental and validation process, allowed significant interactive audience participation, and participant feedback on the program and its value to the hematopathologist working with MDS.

Accurately enumerating blast cells, essential for prognostic assessment and treatment stratification of MDS, is often difficult, due to imprecise criteria for the morphological definition of blasts and promyleocytes. The diagnosis of early stages of MDS is also problematic, due to a lack of minimal diagnostic criteria.

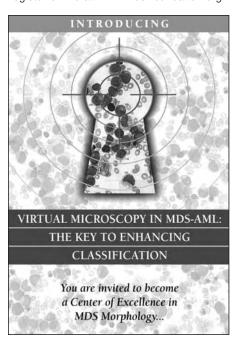
The French-American-British (FAB) Classification system served as the standard for MDS classification for two decades and still provides considerable prognostic/ diagnostic information. The International Prognostic Scoring System (IPSS) provides a prospective risk assessment from the initial diagnosis but is dependent on having both an accurate bone marrow blast assessment and cytogenetic analysis. Increasing blast percentages (5-10, 1-20, 20-30) increase the risk of death from all causes and leukemic transformation. The World Health Organization (WHO) proposed a revision to the FAB morphologic approach. These revisions included lowering the threshold for the percentage of blasts required to make the diagnosis of AML from 30% to 20%.

All of these classification systems depend critically on an assessment of dysplastic changes in the marrow and the percentage of marrow blasts to stratify patients. It is assumed that the blast definitions described by the FAB system are being used uniformly by hematologists/pathologists worldwide, and that blasts could be identified and counted very easily. In actual practice, however, this is not the case.

In 2003, an International Working Group (IWG) of hematopathologists, hematologists and experts in the field of MDS reviewed the morphological features of bone marrows from all the subtypes of MDS and agreed on a set of recommendations. This multisegment CME program is intended to assist pathologists in becoming experts in the classification of MDS patients.

At the end of this series, participants will understand the need for morphologic expertise in the classification of MDS; understand the methodology/validation used to develop new cell definitions in MDS, understand the changes in cell definitions suggested by expert concordance, and have the ability to effectively complete the full CME program utilizing virtual microscopy.

To receive program informational materials please call 1-800-MDS-0839 or register online at www.mds-foundation.org.



MDS in Saudi Arabia

November 13–15, 2007 Riyadh, Saudi Arabia

On November 13–15 the MDS Foundation was privileged to participate in the *International Congress on Bone Marrow and Stem Cell Transplantation* in Riyadh, Kingdom of Saudi Arabia. We participated with support from Novartis Oncology and at the personal invitation of Drs. Hassan El-Solh (Chairman of the Organizing Committee) and Dr. Mahmoud Aljurf (Chairman of the Scientific Committee) of King Faisal Specialist Hospital and Research Center.

The Organizing Committee anticipated that 600 to 700 nurses and physicians would attend this meeting. The reality was more than 1400 attendees! The participants included HSCT and hematology leaders from Africa, Asia, and Eastern Mediterranean countries. In addition to the main scientific forum an entire day was devoted to a nursing forum for nurses working in HSCT. The topics covered stem cell biology, acute leukemia chronic myeloid malignancies, lymphoid malignancies, bone marrow failure and hemoglobin disorders, immunodeficiency, cord blood transplants, GVHD, infections in transplant and translational research.

With the huge unanticipated attendance everyone at King Faisal worked 'overtime' to insure that this meeting was flawless. Our experience was certainly that—flawless! The scientific sessions were excellent and many people from around the world participated as members of both the Scientific Program Faculty and the Nursing Forum Faculty for this program.

We were also treated to wonderful meals and an opportunity to see Riyadh as it existed 50 years ago. The transcendence of this truly cosmopolitan city from the rural farming based community of 40 years ago to the metropolitan and technologically advanced area that it is today is truly remarkable.

The Foundation's booth was welcomed with open arms by the participants and we came home empty handed from this meeting with many requests for information to fulfill following the meeting. On behalf of the

Foundation I would like to thank everyone who assisted us so readily during our visit! This was a remarkable meeting run by a group of remarkable people who truly put Riyadh and King Faisal on the 'map' of key hematology and bone marrow transplant centers worldwide.



Maha Sabbagh of Novartis Oncology and her Saudi Arabian colleagues.



The Head of Public Relations from King Faisal.



Dr. Aljurf (right) and one of the Symposium attendees.



The wonderful Public Relations group who made our stay and the meeting memorable.

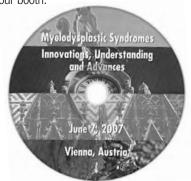
SATELLITE SYMPOSIUM

12th Congress of the European Hematology Association

June 7–10, 2007 Neue Messe Convention Centre Vienna, Austria

Myelodysplastic Syndromes— Innovations, Understanding and Advances

The Myelodysplastic Syndromes Foundation presented its second adjunct symposium at The European Hematology Association 12th Annual Meeting in Vienna. The symposium was greeted by standing room only, 1000 copies (on CD-ROM) were distributed on Friday and Saturday of the EHA meeting. This educational video and the accompanying slides will be provided to audiences both via our Educational website and on CD for continued use throughout 2007. Translations of educational materials in Czech, Dutch, French, German, Greek, Hungarian, Italian, Japanese, Polish, and Spanish were also provided free of charge at our booth.



For a copy of the CD ROM, which contains all of the slide presentations from this session, please contact the MDS Foundation at 1-800-MDS-0839.

AGENDA

- Introduction: Ghulam J. Mufti, MD
- Growth Factors: Impacting Survival in MDS? Eva Hellström-Lindberg, MD, PhD
- MDS Prognosis—Unveiling a Real-Time Assessment Tool: Luca Malcovati, MD





The Neue Messe Convention Centre

- The Role of Reduced-Intensity Regimens in High-Risk MDS: Decision Guidelines Theo J.M. de Witte, MD, PhD
- Epigenetic-Basis for Treatment in MD Jean-Pierre Issa, MD
- Current Revisions to WHO: Clinical Implications John M. Bennett, MD
- Summary and Q&A Pierre Fenaux, MD

Learn More About MDS: Join the Journey to Hope for MDS

- MDS is a puzzling, life-threatening group of diseases of the bone marrow for which there are no easy cures or quick remedies.
- The most common of all the cancers related to the blood system, it is estimated there are more than 30,000 new MDS cases each year in the United States alone. We believe this is vastly underestimated.
- Despite more than three decades of dedicated research, the causes of MDS remain largely unknown.
- MDS is largely unknown to the general public.
- For roughly 30% of the patients diagnosed with MDS, these diseases will progress to acute myeloid leukemia (AML), a type of bone marrow malignancy which does not respond well to chemotherapy.
- Until recently treatment consisted only of supportive care including blood transfusions (red blood cells or platelets), and treatment with growth factors like erythropoietin (EPO) with

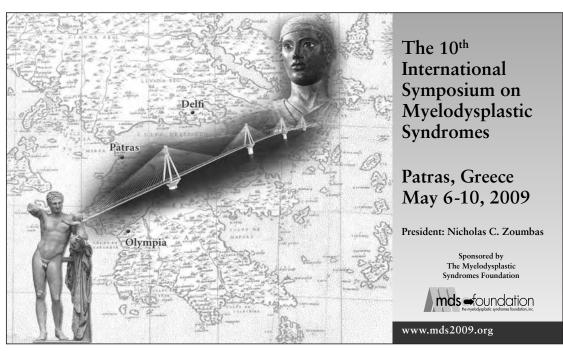
G-CSF or GM-CSF. There are now three drugs approved for the treatment of MDS: Vidaza® (azacitidine), Dacogen® (decitabine), and Revlimid® (lenalidomide). At present, there are two FDA-approved drugs for the treatment of transfusion-dependent iron overload: Exjade® (deferasirox) and Desferal® (deferoxamine). None of these are curative.

How to Help:

- Bone marrow transplantation is often the only chance of survival. Nearly 70% of the patients are without a match. The need is especially critical in racial and ethnic minority groups.
- As a not-for-profit organization, the MDS Foundation depends entirely on public funding in the form of individual gifts, donations from individual and corporate entities, and membership fees to further our work.
- To learn how to support the MDS Foundation, go to the Foundation's website at www.mds-foundation.org.

Foundation Plans International Symposia Through 2013

The MDS Foundation has approved applications for the next three International Symposia. These symposia are scheduled for 2009 in Patras, Greece; 2011 in Edinburgh, Scotland, and 2013 in Berlin, Germany.



CALL FOR ABSTRACTS: DEADLINE 30 JANUARY 2009 Upcoming: Preliminary program on abstract submission, registrated and excursions will be available.

SECOND ANNOUNCEMENT

Upcoming: Preliminary program including information on abstract submission, registration, accommodation, and excursions will be available on March 15, 2008 at www.mds2009.org and www.epsiloncongress.gr

Local Organizing Secretariat: EPSILON

4 Papadiamantopoulou Str. 115 28 Athens, Greece E-mail: info@epsiloncongress.gr www.epsiloncongress.gr

Scientific Secretariat: mds2009@epsiloncongress.gr

The 10th
International
Symposium on
Myelodysplastic
Syndromes

Patras, Greece May 6-10, 2009

President: Nicholas C. Zoumbas

www.mds2009.org

Tenth International Symposium: Spring 2009

Patras, Greece

Sponsor:

Nicholas C. Zoumbos, MD

Eleventh International Symposium: Spring 2011

Edinburgh, Scotland

Sponsor:

David T. Bowen, MD

Twelfth International Symposium: Spring 2013

Berlin, Germany

Sponsor:

Wolf-Karsten Hofmann, MD, PhD

Patient Information

Medical Glossary of Terms Relating to MDS

Written for Patients

Sometimes it seems that you have to learn a completely new language to understand what your physicians and nurses are telling you about MDS.

We hope that this list of commonly used medical terms and definitions will help you and your family or support person(s) to understand what these terms mean and help you understand MDS.

GENERAL

Acute: A sudden onset of symptoms or diseases.

Acute myeloid leukemia (AML): A cancer characterized by the rapid proliferation of abnormal cells which accumulate in the bone marrow and interfere with the production of abnormal blood cells. AML is the most common acute leukemia affecting adults, and its incidence increases with age, however it can also occur in children. The symptoms of AML are caused by replacement of normal bone marrow with leukemic cells, resulting in a drop in red blood cells, platelets, and normal white blood cells.

Anemia: A condition in which the number of red blood cells is below normal, resulting in fatigue or weakness.

Antibiotics: Drugs used to stop or slow down the growth of germs.

Antibodies: Proteins that help protect the body against foreign substances.

Apheresis: A procedure in which blood is taken from a donor, a blood component (such as white blood cells, red blood cells, or plasma) is separated out, and the remaining blood components are put back into the donor.

Apoptosis: The self-destruction, or suicide, of cells including cancer cells.

Blast cells: Immature blood cells that normally become fully functional mature red cells, white cells, or platelets.

Blood tests: Blood samples drawn from the arm that are evaluated for cell counts (red cells, white cells (and their subtypes), and platelets. The blood is also evaluated for the shape and size of the red and white blood cells and the level of erythropoietin in the serum.

Bone marrow: The soft, sponge-like tissue in the center of bones that functions like a factory to produce white blood cells, red blood cells, and platelets.

Bone marrow aspirate: A sample of the liquid portion of the bone marrow.

Bone marrow aspiration: The process of removing bone marrow from a specific area using a small needle and syringe. Used for making a diagnosis.

Bone marrow biopsy: A sample of the boney portion of the bone marrow.

Chemotherapy: Treatment of a disease with chemical drug agents.

Chromosomes: A structure that contains your genetic information, or DNA. Normally each person has 23 pairs of chromosomes.

Chronic Myelomonocytic Leukemia (CMML): A slowly progressing type of myelodysplastic/myeloproliferative disease in which too many myelomonocytes (a type of white blood cell) are in the bone marrow, crowding out other normal blood cells, such as other white blood cells, red blood cells and platelets.

Clinical trial: A research study designed to evaluate new methods of screening, prevention, diagnosis, or treatment of disease.

Combination chemotherapy: The use of more than one drug during cancer treatments.

Cytogenetics: Testing that is performed on bone marrow samples and examines the chromosomes of the cells. The test gives information about the type of MDS that is present. Common abnormalities include:

- 1. Deletion 5q—deletion of chromosome 5
- 2. Deletion 20—deletion of chromosome 20
- 3. Deletion Y—deletion of Y chromosome
- 4. Monosomy 7—loss of one of the two 7 chromosomes
- 5. Trisomy 8—addition of a third chromosome 8

Cytopenia: A deficiency of (or too few) mature cells in the blood. Deficiencies can occur in red cells, white cells, and/or platelets.

Differentiation: The process of cells maturing to become healthy adult cells of a particular type (i.e. red cells, white cells, and platelets).

Dysplasia: Abnormal shape and appearance, or morphology, of a cell.

Erythropoietin: A protein substance manufactured by the kidneys in response to low oxygen levels in body tissues. Erythropoietin stimulates the production of red blood cells in the bone marrow.

FAB Classification: The classification of MDS by the French-American-British (FAB) group. (See page 9 of the MDS Foundation's Patient Handbook Understanding Myelodysplastic Syndromes)

Fatigue: A feeling of low or no energy, general feeling of tiredness with normal activity.

Ferritin (Serum) or ferritin level: The major iron storage protein found in the intestinal mucosa (lining), spleen, and liver. The blood level of ferritin serves as an indicator of the amount of iron stored in the body. It is expressed as ng/mL or nanograms of iron per milliliter of blood. Normal range of serum ferritin is 20 ng/mL to 300 ng/mL in men and 12 ng/mL to 150 ng/mL in women.

Hematocrit: Percent of the total blood volume that is made up of red blood cells. In men a normal hematocrit is 40–52% while in women the normal is 36–46%. (See red blood cells)

Hematologist: A doctor who specializes in the diseases and disorders of blood.

Hematopoiesis: The formation and development of blood cells in the bone marrow.

Immature blood cells: May be called stem cells, progenitor cells or blasts.

Immune system: The complex group of organs and cells that defends the body against infection and disease.

Immunosuppressive drug: Drug given to suppress a patient's immune system, such as one given to prevent rejection of transplanted tissue.

IPSS: International Prognostic Scoring System—system for grading the severity of MDS. (See page 11 of the MDS Foundation's Patient Handbook Understanding Myelodysplastic Syndromes)

Iron Overload: Too much iron in the body which can then build up in the organs and cause disease. It is a particular risk in people with certain genetic disorders such as hemochromatosis and people receiving repeated blood transfusions.

Myelo: A Greek word meaning marrow.

Myelodysplastic syndromes: A group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells.

Neutropenia: A deficiency (below-normal number) of mature white blood cells (neutrophils).

Packed RBCs: A concentrated blood product in which most of the plasma, the fluid part of blood, is removed to make red blood cell transfusions easier and faster.

Pediatric MDS: MDS is rare in children; but it does happen. Most patients are 60 years old or older.

Peripheral blood stem cell (PBSC): Stem cells collected from the blood. The term "peripheral" means that the cells come from outside the bone marrow.

Platelets: Irregularly shaped, colorless cells that are present in blood. Their sticky surface lets them, along with other substances, form clots to stop bleeding. Also called thrombocytes. Stated as Platelets/ μ L of blood. Normal range 150,000–450,000.

Remission: Disappearance of the signs and symptoms of cancer. A remission may be complete (CR) or partial (PR).

Serum erythropoietin: Amount of erythropoietin that is present normally in an individual's blood.

Stem cells: Cells that are produced in the bone marrow and develop into either red blood cells, white blood cells, or platelets.

Thrombocytopenia: A condition in which the number of mature platelets, or thrombocytes, is below normal, resulting in the tendency to bruise and bleed more easily.

Transfusion: Process by which blood or one of its components is delivered directly into the bloodstream.

White blood cells: Cells produced in the bone marrow and lymph nodes. White cells are key cells in the immune system that prevent or fight infection. Normally stated in cells/µL. Normal range is 3,200-10,000.

World Health Organization (WHO) Classification: Expanded categories of MDS based on the FAB Classification System. (See page 9 of the MDS Foundation's Patient Handbook Understanding Myelodysplastic Syndromes)

RED BLOOD CELLS

Erythrocyte: A red blood cell. It carries oxygen to body cells and carbon dioxide away from the cells. (See red blood cells)

Red blood cells: Cells, in the blood, that carry oxygen to your tissues.

WHITE BLOOD CELLS

ANC (absolute neutrophil count): A measure of the actual number of mature neutrophils in a given volume of blood.

Basophil: Type of white blood cell that plays a role in allergic reactions.

Eosinophil: Type of white blood cell that kills parasites as well as playing a role in allergic reactions.

Granulocyte: A term for any of the white blood cell types that have granules containing enzymes to help fight infection: neutrophils, eosinophils and basophils.

Lymphocytes: Small white blood cells produced in the lymphoid organs (the lymph nodes, spleen, thymus, and tonsils) that are essential for normal function of the immune system.

Monocyte: A white blood cell that helps the body fight infections from bacteria and viruses. (See white blood cells)

Neutrophil:

A type of white blood cell that functions to destroy bacteria.

BONE MARROW BIOPSY

Biopsy: The removal and examination of a small piece of tissue from the body to determine a precise diagnosis.

Iliac crest: The hip bone area from which bone marrow samples are most commonly taken.

BONE MARROW TRANSPLANT

Allogeneic stem cell transplantation:

A procedure in which bone marrow or peripheral blood stem cells from a donor (usually related) are collected, stored, and infused into a patient (recipient) following high-dose chemotherapy or radiation therapy.

Allograft: An allogeneic stem cell transplant.

Autograft: An autologous stem cell transplant.

Autologous stem cell transplantation: A procedure in which a patient's own stem cells from bone marrow or peripheral blood are collected, stored, and reinfused following high-dose chemotherapy or radiation therapy.

Bone marrow transplant: A procedure in which a patient's bone marrow is destroyed by high doses of chemotherapy or radiation therapy to eradicate disease and then replaced with healthy bone marrow from a donor or the patient himself.

Engraftment: The process by which stem cells in transplanted bone marrow or blood migrate to the recipient's bone marrow and begin to grow and produce new white blood cells, red blood cells, and platelets.

Graft-versus-host disease (GVHD): Complication of allogeneic transplants resulting from donor leukocytes recognizing the recipient's cells as foreign and mounting an attack against them.

Mini-allograft: Type of allogeneic stem cell transplant that uses lower doses of chemotherapy or radiation and thus does not completely destroy the bone marrow; also known as mini-transplant or non-myeloablative transplant.

Mini-transplant:

See mini-allograft.

Myeloablation: The killing of bone marrow by radiation or chemotherapy. This term usually refers to the complete or near-complete destruction of the bone marrow.

Non-myeloablative transplant:

See mini-allograft.

DRUG TREATMENT

Antibiotic therapy: Used to treat bacterial infections or prevent recurrence of bacterial infections.

Antithymocyte globulin (ATG): Is an immunosuppressive agent that eliminates abnormally proliferating white blood cells called T lymphocytes which disrupt normal blood cell growth. This may restore normal red blood cell maturation which may lead to transfusion independence. The three brand-name drugs are Thymoglobulin® Lymoglobulin®, and Atgam®.

Colony-stimulating factor (CSF): Protein that stimulates the development and growth of blood cells; sometimes called growth factor. Granulocyte colony-stimulating factor is a CSF that is used to mobilize stem cells from the bone marrow into the bloodstream prior to apheresis.

Corticosteroids: Also called "steroids," corticosteroids are powerful anti-inflammatory agents used to treat many diseases and conditions. They are similar to a protein called cortisol that is made in the adrenal glands. Some corticosteroids that you may have heard of are prednisone and dexamethasone.

Dacogen™ (decitabine): Works by preventing certain genes involved in controlling cancer from being silenced, allowing for the normal functioning of the tumor suppressor genes. It is a DNA hypomethylating agent that is administered intravenously (IV), directly into the vein.

Desferal® (deferoxamine): It binds to iron and promotes its removal from the body for treatment of transfusion-dependent iron overload. It is an iron-chelating drug that is administered subcutaneously, into the deeper layer of the skin.

Erythropoietin (EPO): Is a "recombinant" form of a natural growth factor used to treat symptoms associated with anemia. It stimulates the bone marrow to produce red blood cells. The three brand-name drugs are Aranesp®, Epogen®, and Procrit®. These drugs are administered intravenously, directly into the vein, or subcutaneously, into the deeper layer of the skin.

Exjade® (deferasirox): It binds to iron and promotes its removal from the body for treatment of transfusion-dependent iron overload. It is an iron-chelating drug that is administered orally (by mouth).

Growth factors (hematopoietic):Substances that stimulate blood cells to grow.
G-CSF and GM-CSF are two of these factors.

Hycamtin® (topotecan hydrochloride): Is a chemotherapy agent that may result in remission of MDS. It is administered intravenously, directly into the vein.

Leukine® (sargramostim): Is a granulocyte macrophage colony-stimulating factor (GM-CSF) used for the treatment of neutropenia. It increases white cell production, which may help to reduce the likelihood of additional infection. It is administered subcutaneously, into the deeper layer of the skin.

Neupogen® (filgrastim): Is a granulocyte colony-stimulating factor (G-CSF) used for the treatment of neutropenia. It increases white cell production, which may help to reduce the likelihood of additional infection. It is administered subcutaneously, into the deeper layer of the skin.

Pyridoxine (Vitamin B₆): Can relieve sideroblastic anemia through increases in red cell counts. Patients can take 100 mg of vitamin B₆ twice a day orally (by mouth).

Revlimid® (**Ienalidomide**): Works by stimulating the immune system, inhibiting new blood vessel growth, and causing cell death. It is categorized as an immuno-modulatory agent and is administered orally (by mouth).

Telintra[™] (TLK199): Stops a key enzyme (glutathione S-transferase P1-1 or GST P1-1) involved in cell growth and division, thereby promoting normal growth and development of all blood cell types. It is administered intravenously, directly into the vein.

Thalomid® (thalidomide): Reduces the blood supply in the marrow, thereby working to limit the growth and spread of abnormal cells. It also acts to thwart cytokines that promote premature death of progenitor cells in the bone marrow. It is administered orally (by mouth).

Trisenox® (arsenic trioxide): Inhibits new blood vessel growth and stimulates cell death. May increase transfusion independence. It is administered as an intravenous infusion, directly into the vein.

Vidaza[™] (azacytidine): Works by preventing a cellular process (methylation) that silences the genes involved in controlling the development of cancer. It increases red blood cells, transfusion independence, hemoglobin, white blood cells, platelets, and/or decreases bone marrow blast percentage. It is categorized as a DNA hypomethylating agent and can be administered intravenously, directly into the vein, or subcutaneously, into the deeper layer of the skin.

Practice and Treatment Survey

The Myelodysplastic Syndromes Foundation would like to know more about your approach to the diagnosis and treatment of patients with MDS. Please assist us by completing a brief online survey.

Go to www.mds-foundation.org and click on Practice & Treatment Survey

Patient Forums and Support Groups

Patient and Family Forum Held in Florence, Italy May 19, 2007

The conference was free of charge and open to all patients with myelodysplasia and their families or guests. Attendees were given an opportunity to actively participate and to share their thoughts concerning problems and lifestyle changes related to living with MDS. Doctors involved in MDS research provided information on MDS and new treatment options. In addition, participants had the opportunity to meet other patients allowing everyone the opportunity to share their stories and concerns.

We would like to thank the faculty as this program generated excellent audience interest and attendance.

PROGRAM

- Living with Myelodysplasia:
 The Quality-of-Life Problem
 Kathy Heptinstall,
 Operating Director,
 The MDS Foundation
- Epidemiology

 Professor Sante Tura
- Support TherapyProfessor Rossi Ferrini
- Available Therapies and Future Options
 Professors Mario Cazzola and Valeria Santini
- Staminal Cell Transplantation in Myelodysplasia
 Professor Alberto Bosi

Mayo Clinic Researcher Presents MInnesota Patient Forum



Dr. David Steensma, Mayo Clinic

Rochester, Minnesota

On June 28, 2007, MDS patients and their families had the opportunity to hear a presentation from Dr. David Steensma, a leading MDS researcher, from Mayo Clinic in Rochester, Minnesota. Dr. Steensma did a wonderful job presenting information regarding new therapies, and the latest in medical research. He indicated that new research has greatly enhanced understanding of pathophysiology of MDS and new treatment modalities have been developed. Attendees were also able to ask him questions and have their particular concerns addressed. These Forums are being used to develop educational information for physicians focused on the issues that are most important to patients living with MDS and helpful information for patients living with this disease. Patients and their guests exchanged information and made friends. These patient forums have been very well received by both the physicians, patients and their caregivers.



Funding has been obtained to support these ongoing meetings and we are actively recruiting patients to facilitate and participate in these groups. Patients, family members, and caregivers are invited to join. If you are interested in joining an existing group or starting a new group in your area, please contact:

Audrey Hassan Patient Liaison, MDS Foundation patientliaison@mds-foundation.org or call 1-800-MDS-0839.



Minnesota Patient and Family Forum Attendees.



Dr. Steensma addressing patients and their guests in Rochester, Minnesota.



Share Your Stories with the MDS Community

The Foundation would like to invite patients and their families to share their stories with others in the MDS community. Living with MDS poses challenges and many of you have stories that provide hope to others.

Please contact the Foundation, if you would like us to publish your story!!!

My Story...

Bill Stroup Jacksonville, Florida

My name is Bill Stroup, a 70-year old retired university chaplain living in Jacksonville, Florida. A 10-year prostate cancer survivor with recent bone metastases, I did not respond well to chemotherapy (my WBC dropped to 550 and my temp rose to 104°+ after only two treatments), so my oncologist and I chose to treat the spinal metastases with radiation. Two months following my 51st radiation treatment over that 10 year period, my hematology results began sliding lower on each weekly visit. On May 15, 2007, bone marrow aspiration/biopsy results revealed MDS. It's amazing how my entire family's focus moved from the symptoms and treatment of metastatic cancer to the understanding and management of this new diagnosis. We had never even heard the term. It was almost as if the "cancer" no longer mattered: myelodysplasia and all of its ramifications took center stage.

Being an optimistic man with strong religious faith, I sought to amend my layman's comprehension of clinical reports through a linguistic hobby, original word study: I decided to look up the meaning of myelodysplastic syndrome in my Greek lexicon and to also see where these terms appeared in the New Testament writings of the Bible. Not only has this exercise

broadened my understanding of what's going on in my body, it has enabled my family and friends to develop an enlightened overview of MDS and it has kept them from volunteering an unending list of well-meaning but ineffective therapies.

Myelo is the Greek word for "bone marrow." Plasia is both a verb for "forming" and a noun for "something formed." Syndrome comes from a term meaning "run together." The Dys is a prefix that turns any word into its negative opposite. The Biblical references have nothing to do with MDS specifically, but give perspective to our current usage. The Word of God is said to be sharper than a two-edged sword in its ability to divide between joints and marrow; the term plasia appears with reference to Adam who was formed before Eve; and syndrome is used to describe how lots of people ran together flocking around Jesus or his disciples whenever a miracle was performed. It's the prefix, dys, that identifies the pathological nature of MDS. The marrow which is supposed to form good blood cells from stem cells not only fails to do so in required quantities and quality, it is so compromised in its manufacturing function that it systematically mis-forms whatever cells are generated. These inferior cells either die in the marrow or shortly after entering the blood stream, cluttering it up with "blasts." The net result? the entire body joins in as each organ and function irretrievably declines. Chemical signals calling for more production literally and figuratively "fall on deaf ears."

I have begun a few blood transfusions but the positive results are meager and short-lived. Hospice services have been engaged and I am encouraged daily by these word studies, contact with friends and my faith. Thanks for the contributions of the MDS Foundation.

Join the Journey to Hope Bracelets

In loving memory of her mother and sister who passed away from MDS, Sandy Madrigal has created handcrafted bracelets dedicated to promoting awareness to MDS.

Each bracelet is made with a combination of Swarovski crystals, with fine Japanese glass beads, antique Rhodium (a lead-free pewter), silver plated and sterling silver accents.

GIVE A GIFT OF HOPE...

10% of the sale of each bracelet will be donated to the MDS Foundation



To order for only \$20.00, please visit www.lovinkissesbeading.com and email sandy@lovinkissesbeading.com or call 800-MDS-0839.

A \$2.00 shipping and handling fee will be applied to each order. International orders may have additional shipping costs.



Novartis has provided the MDS Foundation with an educational grant to support the Foundation's work.

Drug News

Vidaza Significantly Extends Overall Survival by 74% in Phase 3 Trial in Myelodysplastic Syndromes (MDS)

- Two year survival rate of 50.8 percent for Vidaza versus 26.2 for conventional care regimens
- 9.4 months median survival benefit for patients on Vidaza compared to conventional care regimens
- Only agent to demonstrate survival benefit in MDS compared to conventional care regimens
- Only epigenetic modifier to show survival benefit in cancer
- Stratified log-rank *P*-value = 0.0001, Hazard ratio = 0.58
- Largest study ever conducted in higherrisk MDS

On August 2, 2007, Pharmion Corporation announced in their press release topline results from the multi-institutional, international, randomized, Phase 3 controlled trial of Vidaza® (azacitidine for injection) versus conventional care regimens (CCR) in the treatment of patients with higher-risk myelodysplastic syndromes (MDS). In the primary endpoint analysis, Vidaza treatment was associated with a median survival of 24.4 months versus 15 months for those receiving CCR treatment, an improvement of 9.4 months with a stratified log-rank P-value of 0.0001. The hazard ratio describing this treatment effect was 0.58 (95 percent confidence interval of 0.43 to 0.77). Twoyear survival rates were 50.8 percent versus 26.2 percent for patients receiving Vidaza versus CCR (P < 0.0001). Median number of treatment cycles was nine for Vidaza.

The survival benefits of Vidaza were consistent regardless of the CCR treatment option (best supportive care (BSC) alone, low-dose cytarabine plus BSC or standard

chemotherapy plus BSC) utilized in the control arm.

"These landmark results, showing a significant improvement in survival in the most advanced MDS patients, validate the benefit Vidaza can provide patients with this extremely difficult to treat disease," said Dr. Lewis R. Silverman, Associate Professor of Medicine, Division of Hematology and Medical Oncology, Mount Sinai School of Medicine. "Building on the established data from our earlier clinical studies, which showed that Vidaza offers transfusion independence to many patients with MDS, we now see that Vidaza not only improves a patient's life, but extends it as well."

"With these very exciting results for Vidaza, survival should now be the standard by which we evaluate treatment options for higher-risk MDS," said Dr. Alan F. List, Chief, Malignant Hematology Division and Deputy Physician in Chief, H. Lee Moffitt Cancer Center and Research Institute. "Importantly, as the first and only epigenetic therapy to have demonstrated a survival benefit in any cancer, these findings should accelerate exploration of Vidaza in other malignancies where hypermethylation is believed to play a key role in tumor development and progression."

"We are extremely gratified with the results from the Vidaza Survival Study, which for the first time bring the hope of prolonged survival for patients with higher-risk MDS," said Patrick J. Mahaffy, Pharmion's chief

executive officer and president. "As the only therapy to have ever demonstrated a survival advantage in MDS, and especially to have demonstrated an improvement of this magnitude, Vidaza is unique in the treatment for this disease."

Pharmion expects to present full study results at an upcoming medical meeting. Based on these results, Pharmion intends to file a Marketing Authorization Application (MAA) in the European Union (EU) for Vidaza for the treatment of higher-risk MDS before the end of this year and will shortly thereafter submit additional international regulatory submissions. The Company will also file a supplemental New Drug Application (NDA) with the U.S. Food and Drug Administration (FDA) to include these data in the prescribing information in the U.S.

Pharmion is also developing a next generation product, oral Azacitidine, for the treatment of MDS and other cancers where demethylation can provide an anti-tumor effect. Oral Azacitidine is the subject of a Phase 1 multi-center, open label dose escalation trial that will assess the maximum tolerated dose, dose limiting toxicities and safety of a seven day, multi-cycle oral dosing regimen of oral Azacitidine in patients with MDS and AML. In addition, the trial will examine pharmacokinetics and pharmacodynamic effects of orally administered Azacitidine, as compared with parenteral Vidaza.

Purchase MDS Awareness Pins

The MDS Foundation has enameled lapel pins for you to wear with pride and to increase public awareness about MDS. The pins are available with a \$3.99 donation to The MDS Foundation. To order your pins, call The MDS Foundation at 1-800-MDS-0839.



This item was created especially for The MDS Foundation

to contribute to the effort to help people worldwide living with myelodysplastic syndromes. Your donation will help increase awareness of this little known disease, which is the most common of the hematologic malignancies. **Please ask your family and friends to wear these pins in support of our mission!**

CMS Decision on Proposed Removal of Aranesp, Epogen, and Procrit from Medicare Reimbursement

The Centers for Medicare and Medicaid Services (CMS) has retreated from its initial position of denying patients suffering from myelodysplastic syndromes (MDS) coverage for erythropoietin stimulating agents (ESAs).

The response from both the medical and MDS patient communities was overwhelmingly critical of the proposed reimbursement changes that would have denied coverage to MDS patients being treated with ESAs (Epogen, Aranesp, Procrit), the majority of whom are over the age of 65.

The MDS Foundation addressed this issue from many different aspects including submission of key scientific documentation regarding the use of ESAs in MDS to CMS,

alerts to patients regarding the need for MDS patients, their families, and friends to respond to CMS directly (which they did in record numbers), testimony and consultations offered to CMS from physicians and researchers working in the field of MDS, testimony before the Oncology Drug Advisory Committee of the FDA by Steven Gore, MD of Johns Hopkins University, and direct correspondence and personal discussion with members of key Congressional and Senate Committees.

CMS made no recommendation regarding the coverage of ESAs for MDS. This means that local Medicare contractors will make individual decisions regarding coverage for ESAs for MDS patients.

An MDS patient and a Member of the Foundation's Board of Directors, Robert Weinberg said that, "From the standpoint of the MDS patient community, we welcome recognition by our congressional representatives of the important role played

by erythropoiesis-stimulating agents in the treatment of anemia caused by MDS. We will be relieved when all threats are removed to the availability of these agents for MDS patients."

Even though the public comment period for CMS has ended, it is still important for you to contact your U.S. Representative! Members of Congress do not support these types of resolutions unless they hear from their constituents. Tell them this is unfair to MDS patients in the United States. Spread the word and contact your elected Representative today!

Please continue to monitor our website, www.MDS-Foundation.org for information regarding this issue and others of importance to MDS patients worldwide. If we can assist you in any way (including information on the use of ESAs in MDS) please do not hesitate to contact us via e-mail at:

patientliaison@mds-foundation.org or by phone at 800-MDS-0839.

Be a Bone Marrow Donor

For those patients diagnosed with a fatal blood disorder, bone marrow transplantation (BMT) is often the only chance of survival. Related donors provide suitable matches only 33 percent of the time. This leaves nearly 70 percent of patients without a match. The need is especially critical in racial and ethnic minority groups.

Registering as a donor is simple. A blood sample is all you need to enter your tissue type into the National Marrow Donor Program (NMDP) computerized registry. If you are in good health and between the ages of 18 and 55, you can contact NMDP at 1-800-MARROW-2. They will send additional information, including the NMDP center nearest you. **Give the Gift of Life!**

Other sites of interest:

ASBMT™ American Society for Blood and Marrow Transplantation: www.asbmt.org

International Bone Marrow Transplant Registry: www.isbmtr.org

National Marrow Donor Program®: www.marrow.org

Blood & Marrow Transplant Information Network: www.bmtinfonet.org

Blood & Marrow Transplant Resources: www.BMTresources.org

Over 140 Things You Need to Know about Your Autologous Bone Marrow or Stem Cell Transplant is available online at www.BMTresources.org or call (414) 870-4850, ISBN# 0-9768060-0-2/Price: \$11.95. Contains over 140 invaluable tips to help transplant patients sail through their procedures.

Patient Registries and Referrals

MDS Patient Registry

The patient registry form has been revised and a patient authorization form has been developed to meet HIPAA guidelines. The Patient Registry will help further research into the etiology, diagnosis and treatment of MDS. Currently, the MDS Patient Registry is only accepting patients through our designated Centers of Excellence. A two page data sheet will be forwarded to investigators who wish to contribute patient's names to the Registry. The Registry is located at the MDS Foundation's Statistical Center at the University of Rochester Cancer Center.

The Foundation looks forward to building the Patient Registry with our Centers of Excellence.

If you would like to become a Center of Excellence, please contact The Foundation at the address below.

The MDS Foundation, Inc. 36 Front Street, P.O. Box 353 Crosswicks, NJ 08515

Phone: 1-800-MDS-0839 within the US Outside the US only: 1-609-298-6746

Fax: 1-609-298-0590.

Slone Patient Registry

The Slone Epidemiology Center at Boston University is enrolling patients who have recently been diagnosed with myelodysplastic syndromes in a voluntary research project called the Patient Registries at Slone: MDS. The registry gathers important information about the impact of MDS and its treatments on patients' physical, emotional, social, and economic well-being. Participation in the Registry does not affect the care or treatments that patients receive.

You are eligible to join if:

- You have been diagnosed with MDS within the past 3 months
- You live in the US

You do not need to have received any medicines or other treatments for your MDS to be eligible.

For more information or to enroll:

Visit http://www.bu.edu/prs/mds, e-mail mdsinfo@slone.bu.edu or call the registry at 800-231-3769.

Patient Referrals

Myelodysplastic syndromes can be difficult to diagnose and treat. It is important for both patients and their families to know that optimal treatment is available and that quality-of-life can be enhanced.

If you would like information about treatment options, research, or quality-of-life, we would be glad to help. The Foundation offers a variety of patient services, including preferential referrals to the Foundation's MDS Centers of Excellence. We can also help identify physicians and centers to support you if you are travelling and need assistance.

Please contact us at: 1-800-MDS-0839 (phone) or 609-298-0590 (fax).

Outside the US please call: 609-298-1035.

You can visit our website at: http://www.mds-foundation.org.

ICD9 Coding Changes

Changes have been made to the ICD9 codes for MDS. The following sequence reflects the WHO plus the now extinct but still classifiable RAEB-T:

Refractory AnemiaC42.1M-9980/3Refractory Anemia with Ringed SideroblastsC42.1M-9982/3Refractory Anemia with Excess BlastsC42.1M-9983/3Refractory Anemia with Excess Blasts in TransformationC42.1M-9984/3Refractory Cytopenia with Multilineage DysplasiaC42.1M-9985/3Myelodysplastic Syndromes (MDS) with 5q-SyndromeC42.1M-9986/3Therapy-related Myelodysplastic Syndromes (MDS)C42.1M-9987/3Myelodysplastic Syndromes, NOSC42.1M-9989/3	Diagnostic Term	IC	D-0-3
Refractory Anemia with Excess Blasts Refractory Anemia with Excess Blasts in Transformation C42.1 M-9983/3 Refractory Cytopenia with Multilineage Dysplasia C42.1 M-9985/3 Myelodysplastic Syndromes (MDS) with 5q-Syndrome C42.1 M-9986/3 Therapy-related Myelodysplastic Syndromes (MDS) C42.1 M-9987/3	Refractory Anemia	C42.1	M-9980/3
Refractory Anemia with Excess Blasts in Transformation C42.1 M-9984/3 Refractory Cytopenia with Multilineage Dysplasia C42.1 M-9985/3 Myelodysplastic Syndromes (MDS) with 5q-Syndrome C42.1 M-9986/3 Therapy-related Myelodysplastic Syndromes (MDS) C42.1 M-9987/3	Refractory Anemia with Ringed Sideroblasts	C42.1	M-9982/3
Refractory Cytopenia with Multilineage Dysplasia C42.1 M-9985/3 Myelodysplastic Syndromes (MDS) with 5q-Syndrome C42.1 M-9986/3 Therapy-related Myelodysplastic Syndromes (MDS) C42.1 M-9987/3	Refractory Anemia with Excess Blasts	C42.1	M-9983/3
Myelodysplastic Syndromes (MDS) with 5q-Syndrome C42.1 M-9986/3 Therapy-related Myelodysplastic Syndromes (MDS) C42.1 M-9987/3	Refractory Anemia with Excess Blasts in Transformation	C42.1	M-9984/3
Therapy-related Myelodysplastic Syndromes (MDS) C42.1 M-9987/3	Refractory Cytopenia with Multilineage Dysplasia	C42.1	M-9985/3
	Myelodysplastic Syndromes (MDS) with 5q-Syndrome	C42.1	M-9986/3
Myelodysplastic Syndromes, NOS C42.1 M-9989/3	Therapy-related Myelodysplastic Syndromes (MDS)	C42.1	M-9987/3
	Myelodysplastic Syndromes, NOS	C42.1	M-9989/3



Would you like your treatment center to become part of the referral system for MDS patients and be designated as a Center of Excellence? To be recognized as a Center of Excellence, an institution must have the following:

- An established university (or equivalent) program
- Recognized morphologic expertise in MDS
- Available cytogenetics and/or molecular genetics
- Ongoing research, including Institutional Review
- Board—approved clinical trials
- Documentation of peer-reviewed publications in the field
- The ability and intention to register patients in the MDS International Registry database

Please contact the Foundation for further information and an application form for your center.

The following centers have qualified as MDS Centers of Excellence:

UNITED STATES

ALABAMA

University of Alabama at Birmingham Comprehensive Cancer Center

Birmingham, Alabama James M. Foran, MD

ARIZONA

Mayo Clinic Hospital

Phoenix, Arizona James L. Slack, MD

University of Arizona Arizona Cancer Center

Tucson, Arizona

Daruka Mahadevan, MD, PhD

CALIFORNIA Codare-Sinai Me

Cedars-Sinai Medical Center UCLA School of Medicine

Los Angeles, California H. Phillip Koeffler, MD

City of Hope National Medical Center

Duarte, California Stephen J. Forman. MD

Stanford University Medical Center

Stanford, California
Peter L. Greenberg, MD

UCLA Center for Health Science UCLA School of Medicine

Los Angeles, California Gary J. Schiller, MD

University of Southern California Keck School of Medicine

Los Angeles, California Allen S. Yang, MD, PhD

FLORIDA

Mayo Clinic

Jacksonville, Florida Alvaro Moreno-Aspitia, MD

University of South Florida, H. Lee Moffitt Cancer Center and Research Institute

Tampa, Florida Alan F. List, MD

ILLINOIS

Loyola University Chicago Cardinal Bernardin Cancer Center

Maywood, Illinois Scott E. Smith, MD, PhD

Robert H. Lurie Comprehensive Cancer Center of Northwestern

University Feinberg School of Medicine

Chicago, Illinois Olga Frankfurt, MD

Rush University Medical Center

Chicago, Illinois

Stephanie A. Gregory, MD/Jamile Shammo, MD

University of Chicago Medical Center

Chicago, Illinois Richard A. Larson, MD

INDIANA

Indiana University Medical Center

Indianapolis, Indiana Larry Cripe, MD

MARYLAND

Johns Hopkins University School of Medicine

Baltimore, Maryland

Steven D. Gore, MD/Charles S. Hesdorffer, MD

National Heart, Lung, and Blood Institute

Bethesda, Maryland Elaine Sloand, MD

University of Maryland Greenebaum

Cancer Center Baltimore, Maryland

Maria R. Baer, MD/Ivana Gojo, MD

MASSACHUSETTS

Dana-Farber Cancer Institute

Boston, Massachusetts Richard M. Stone. MD

Tufts University School of Medicine New England Medical Center

Boston, Massachusetts Kellie Sprague, MD

MICHIGAN

Barbara Ann Karmanos Cancer Institute Wayne State University

Detroit, Michigan Charles A.Schiffer, MD

William Beaumont Hospital Cancer Center

Royal Oak, Michigan Ishmael Jaiyesimi, MD

MINNESOTA

Mayo Clinic

Rochester, Minnesota David P. Steensma, MD

MISSOUF

Washington University

School of Medicine

Siteman Cancer Center

St. Louis, Missouri John F. DiPersio, MD, PhD

NEBRASKA

University of Nebraska Medical Center

Omaha, Nebraska Lori Maness, MD

NEW JERSEY

The Cancer Center of Hackensack University Medical Center

Hackensack, New Jersey Stuart Goldberg, MD

NEW MEXICO

University of New Mexico

Health Sciences Center Albuquerque, New Mexico *Robert Hromas, MD*

NEW YORK

Albert Einstein College of Medicine Cancer Center

Bronx, New York Amit Verma, MD

Memorial Sloan-Kettering Cancer Center

New York, New York Stephen D. Nimer, MD

Mount Sinai School of Medicine

New York, New York Lewis R. Silverman, MD

New York Medical College/ Westchester Medical Center Zalmen A. Arlin Cancer Center

Valhalla, New York Karen Seiter, MD

North Shore University Hospital

Lake Success New York Steven L. Allen, MD

Roswell Park Cancer Center

Buffalo, New York
Minoo Battiwala, MD
St. Vincent's Comprehensive Cancer Center

New York, New York Azra Raza, MD

University of Rochester Cancer Center Rochester, New York

John M. Bennett, MD

Weill Medical College of Cornell University New York Presbyterian Hospital

New York, New York Eric J. Feldman, MD

NORTH CAROLINA

Duke University Medical Center

Durham, North Carolina

Carlos M. deCastro, MD

Wake Forest University School of Medicine

Comprehensive Cancer Center Winston-Salem, North Carolina

Istvan Molnar, MD

OHIO

Cleveland Clinic Foundation Taussig Cancer Center

Cleveland, Ohio

Jaroslaw Maciejewski, MD, PhD

OREGON

Oregon Cancer Center at Oregon Health and Science University

Portland, Oregon

PENNSYLVANIA

The Western Pennsylvania Cancer Institute

Pittsburgh, Pennsylvania Richard K. Shadduck, MD James M. Rossetti, DO

Thomas Jefferson University Kimmel Cancer Center

Philadelphia, Pennsylvania Emmanuel C. Besa, MD

University of Pennsylvania Cancer Center

Philadelphia, Pennsylvania Selina Luger, MD

UPMC Cancer Centers

University of Pittsburgh Cancer Institute

Pittsburgh, Pennsylvania Anastasios Raptis, MD

TENNESSEE

St. Jude Children's Research Hospital

Memphis, Tennessee Gregory Hale, MD

TEXAS

Southwest Regional Cancer Center Austin, Texas

Richard Helmer, III, MD
University of Texas

MD Anderson Cancer Center Houston, Texas

Elihu H. Estey, MD
University of Texas
Southwestern Medical Center

Dallas VA Medical Center Dallas, Texas Simrit Parmar, MD

WASHINGTON

Fred Hutchinson Cancer Research Center

Seattle, Washington Joachim Deeg, MD

Seattle Cancer Care Alliance University of Washington

Seattle, Washington John A. Thompson, MD

WASHINGTON. DC

Georgetown University Hospital Lombardi Comprehensive Cancer Center

Washington, D.C. Ekatherine Asatiani, MD

MICCONCIN

Medical College of Wisconsin Bone Marrow Transplant Program

Milwaukee, Wisconsin Parameswaran Hari, MD

University of Wisconsin Madison Medical School

Madison, Wisconsin Mark B. Juckett, MD

OUTSIDE THE UNITED STATES

AUOTDALIA

Peter MacCallum Cancer Institute University of Melbourne

East Melbourne, Australia

John F. Sevmour. MD

University of Tasmania Royal Hobart Hospital

Hobart, Tasmania, Australia Raymond M. Lowenthal, MD

AUSTRIA

University Hospital of Innsbruck

Innsbruck, Austria Reinhard Stauder, MD

University of Vienna

Vienna, Austria Peter Valent, MD

BELGIUM

AZ Sint-Jan AV Brugge, Belgium Dominik Selleslaa. MD

University Hospital Leuven

Leuven, Belgium

Michel Delforge, MD, PhD

BRAZI

AC Camargo Hospital - Cancer Center

São Paulo, Brazil

Luiz Fernando Lopes, MD, PhD

Hemocentro da UNICAMP

University of Campinas Campinas, Brazil *Irene Lorand-Metze, MD*

Universidade Federal de Ceará

Ceará, Brazil

Fernando Barroso Duarte, MD

CANADA

Princess Margaret Hospital

Toronto, Ontario, Canada Karen Yee, MD

Toronto Sunnybrook Regional Cancer Centre

Toronto, Ontario, Canada Richard A. Wells, MD

University of Toronto, Hospital for Sick Children

Toronto, Ontario, Canada Yigal Dror, MD

CZECH REPUBLIC

Institute of Hematology & Blood Transfusion

Prague, Czech Republic Jaroslav Cermák, MD, PhD

DENMARK

Odense University Hospital

The University of Southern Denmark

Odense, Denmark Gitte Birk Kerndrup, MD

Rigshospitalet National University Hospital

Copenhagen, Denmark Lars Kjeldsen, MD, PhD

University of Århus The University Hospital

Århus, Denmark

Johan Lanng Nielsen, MD, PhD

FRANCE

Centre Henri Becquerel

Rouen University School of Medicine

Rouen, France Aspasia Stamatoullas, MD

Centre Hospitalier Universitaire (CHU) de Angers, Service des Maladies du Sang

Angers, France Norbert Ifrah, MD

Centre Hospitalier Universitaire (CHU) de Grenoble

Grenoble, France

Jean-Yves Cahn, MD

Centre Hospitalier Universitaire (CHU) de Limoges, Hôpital Dupuvtren

Limoges, France Dominique Bordessoule, MD Centre Hospitalier Universitaire de Nancy

Nancy, France

Agnés Guerci-Bresler, MD, PhD

Hôpital Avicenne/University Paris XIII

Bobigny, France Pierre Fenaux. MD

Hôpital Claude Huriez, CHU Lille Service des Maladies du Sang

Lille, France Bruno Quesnel, MD

Hôpital Cochin/University Paris V

Paris, France Francois Dreyfus, MD

Hôpital Saint Louis/University Paris VII

Paris, France

Christine Chomienne, MD, PhD

Institut Paoli-Calmettes

Marseille, France Norbert Vey, MD

GERMANY

Georg-August-Universität Göttingen

Göttingen, Germany Detlef Haase, MD, PhD

Hannover Medical School Medizinische Hochschule Hannover

Hannover, Germany Arnold Ganser, MD

Heinrich-Heine Universität Düsseldorf University Hospital

Düsseldorf, Germany Ulrich Germing, MD

Johann Wolfgang Goethe Universität

Frankfurt Main, Germany Johannes Atta, MD

MLL Münchner Leukämielabor

Munich, Germany

Saarland University Medical Center

Homburg/Saar, Germany Ulrich Mahlknecht, MD, PhD

St. Johannes Hospital Heinrich-Heine Universität

Duisburg, Germany Carlo Aul, MD, PhD

Albert-Ludwigs-Universität Freiburg

Freiburg, Germany Michael Lübbert, MD, PhD

Universität Hamburg

Hamburg, Germany Nicolaus Kröger, MD, PhD

Universitätsklinikum Carl Gustav Carus

Dresden, Germany Uwe Platzbecker, MD

University Children's Hospital

Freiburg, Germany
Charlotte Niemeyer, MD

Universitätsklinikum Benjamin Franklin

Berlin, Germany

Wolf-Karsten Hofmann, MD, PhD

GREECI

Patras University Hospital

Patras, Greece Nicholas C. Zoumbos, MD

University General Hospital Attikon

Athens, Greece

Theofanis Economopoulos, MD

University of Athens Laikon Hospital Athens, Greece *Nora Viniou, MD* HUNGARY

Semmelweis University School of Medicine

Budapest, Hungary Judit Várkonyi, MD, PhD

IRFI AND

Adelaide and Meath Hospital

Dublin, Ireland Helen Enright, MD

ISRAEI

Tel-Aviv Sourasky Medical Center

Tel-Aviv, Israel

Moshe Mittelman, MD

ΙΤΔΙ Υ

Centro di Riferimento Oncologico di Basilicata (CROB)

Rionero in Vulture (PZ), Italy Pellearino Musto. MD

Istituto di Ematologia Universita' Cattolica Sacro Cuore

Roma, Italy

Giuseppe Leone. MD/Maria Teresa Vosa. MD

University of Florence Azienda OSP Careggi

Florence, Italy Valeria Santini, MD

University of Pavia Medical School

Pavia, Italy Mario Cazzola, MD

University Tor Vergata Ospedale S. Eugenio

Roma, Italy Elisabetta Abruzzese, MD. PhD

JAPAN

Kyoto University Hospital

Kyoto, Japan

Takashi Uchiyama, MD

Nagasaki University Hospital School of Medicine

Atomic Bomb Disease Institute

Nagasaki City, Japan Masao Tomonaga, MD

Nippon Medical School

Tokyo, Japan

Kiyoyuki Ogata, MD, PhD

Saitama Medical School Hospital

Morohongo, Iruma, Japan Akira Matsuda, MD

Tokyo Medical College

Tokyo, Japan

Kazuma Ohyashiki, MD

THE NETHERLANDS

University Medical Center Nijmegen St. Radboud

Nijmegen, The Netherlands Theo J.M. de Witte, MD, PhD

Vriie Universiteit Medical Center

Amsterdam, The Netherlands

Gert J. Ossenkoppele, MD, PhD

POLAND

Jagiellonian University Collegium Medicum

Kraków, Poland Aleksander Skotnicki, MD, PhD PORTUGAL

Hospital de Santa Maria

Lisbon, Portugal Joao F. Lacerda, MD ROMANIA

Fundeni Clinical Institute

Bucharest, Romania Radu Gologan, MD, PhD

SAUDI ARABIA

King Faisal Specialist Hospital

& Research Centre Riyadh, Saudi Arabia Mahmoud Deeb Aljurf, MD

King Khaled University Hospital King Saud University

Ak Almomen. MD

SOUTH AFRICA

Constantiaberg Medi-Clinic Stellenbosch University and Tygerberg Academic Hospital Cape Town, Cape South Africa

Peter Jacobs, MD, PhD
University of Cape Town

Groote Schuur Hospital Cape Town, Cape South Africa *Nicolas Novitzky, MD, PhD*

SPAIN

Hospital Universitario de Salamanca

Salamanca, Spain Jesus F. San Miguel, MD

Hospital Universitario La Fe Valencia, Spain Miguel A. Sanz, MD, PhD Hospital Universitario Vall d'Hebron

Laboratorio del Citologia-Citogénetica

Barcelona, Spain
Maria Teresa Vallespi-Sole, MD, PhD

SWEDEN

Karolinska Institutet

Huddinge University Hospital

Stockholm, Sweden

Eva Hellström-Lindberg, MD, PhD

THAILAND

King Chulalongkorn Memorial Hospital Pathumwan, Bangkok, Thailand

Tanin Intragumtornchai, MD

TURKEY
Ankara University
School of Medicine Hospital

Ankara, Turkey Osman Ilhan, MD

USIIIAII III

UKRAINE
Research Center for
Radiation Medicine

Kiev, Ukraine Dimitry Bazyka, MD

UNITED KINGDOM King's College Hospital University of London

London, United Kingdom Ghulam J. Mufti, MD Leeds General Infirmary

The Leeds Teaching Hospitals Leeds, United Kingdom

David T. Bowen, MD

Queen Elizabeth Hospital
University Hospital Birmingham

NHS Trust Charles Craddock, MD

Sally Killick, MD

Royal Bournemouth Hospital Bournemouth, United Kingdom

Information on Clinical Trials

International Clinical Trials: An Update

NATIONAL CANCER INSTITUTE TRIALS

As we go to press the National Cancer Institute (NCI) has listed more than 100 clinical trials that focus on Myelodysplastic syndromes. Full study information on these trials is available at www.nci.nih.gov. This information includes basic study information, study lead organizations, study sites, and contact information. To access the information:

- Log on to www.nci.nih.gov
- Click on "Finding Clinical Trials"
- On the next screen look for "Ways to Find Clinical Trials" and
- Click on "Search for Clinical Trials"
- Click on "Type of Cancer" and type in 'myelodysplastic syndromes'
- Hit search

This search will provide you with all the trials currently underway in MDS. You may also sort by trials that only focus on treatment or trials that only focus on supportive care.

To view listings of additional studies you can log onto www.clinicaltrials.gov. You can also contact 1-800-4-CANCER for more information.

If you are an MDS patient, you may wish to discuss a trial with your primary treating physician to see if you qualify as a candidate.

Clinical trials study new interventions (drugs or procedures) to evaluate their safety and effectiveness in humans. Trials follow a careful set of steps, allowing for the systematic gathering of information to answer questions and confirm hypotheses that were formed earlier, in either laboratory experiments or preliminary trials.

A clinical trial falls into one of four phases:

Phase I. This is the first time a drug is used in humans. The trial is designed to determine dosage, route of administration

(oral, intravenous, or by injection), and schedule of administration (how many times a day or week). In this phase researchers also begin to determine the drug's safety. The phase I trial is normally conducted in healthy adults and enrolls only a small number of people.

Phase II. Patients with the disease receive the drug at dose levels determined in the earlier phase. The phase II trial begins to determine the effectiveness of the drug and provides more information about its safety.

Phase III. The drug is tested alone or against an approved standard drug. The typical phase III trial enrolls a large number of patients. If it is a comparison trial, patients may be randomly assigned to receive either the new drug or the standard intervention.

Phase IV. In phase IV the drug, already approved by the FDA and available to the public, undergoes continued evaluation. The phase IV designation is rare. Some trials—screening studies evaluating supportive care or prevention—are not conducted in phases. In these trials a group following a certain disease combating strategy, such as a detection method, is compared to a control group.

New Research Protocol Listings

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS and has updated its International Clinical Trials list on our website and for distribution.

For a detailed listing featuring new protocols visit http://www.mds-foundation.org, email patientliaison@mds-foundation.org or call 800-MDS-0839 and the current clinical trials will be sent to you under separate cover.

Clinical trials often have very specific eligibility requirements. Please talk with your doctor to help decide which, if any, trials might be right for you.

Please note that the information is provided strictly as a resource and is not an endorsement of any physician, institution or treatment.

Important Research Study Opportunity

Researchers at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, FL are looking for people who have recently been diagnosed with MDS to participate in a research study designed to better understand why people get myelodysplastic syndrome. Specifically, researchers are studying a part of the chromosome called the telomere to see if telomeres are shorter in people with MDS as compared to people who don't have MDS. A specific gene, called human telomerase reverse transcriptase, or hTERT, will also be studied, to see if hTERT is related to telomere length. People who participate in this study will be asked to complete a questionnaire and provide a blood sample.

Participation in this research study will not in any way affect an individual's medical care or MDS treatment options.

To find out more information about this important research study, please contact Kristen Jonathan at 813-745-8395 or email kristen.jonathan@moffitt.org.



with an educational grant to support the Foundation's work.

Clinical Research/Trial with Lonafarnib-Now Open for Accrual

A Pivotal Randomized Study of Lonafarnib (SCH66366) versus Placebo in the Treatment of Subjects with Myelodysplastic Syndrome (MDS) or Chronic Myelomonocytic Leukemia (CMML) Who Are Platelet Transfusion Dependent With or Without Anemia (Protocol No. P02978)

Study Background

- Lonafarnib (SCH66336) is a potent, orally bioavailable, specific inhibitor of farnesyl transferase. As a farnesyl transferase inhibitor (FTI), Lonafarnib prevents the farnesylation of specific target proteins, including RAS, which are involved in the regulation of cellular proliferation. Preclinical data have documented activity of Lonafarnib against numerous neoplastic cell lines in vitro, including several derived from subjects with myeloid and lymphoid leukemias. Lonafarnib has also inhibited the growth of primary leukemic cells derived from subjects with CMML. These data suggest that Lonafarnib may have clinical efficacy against a variety of hematologic malignancies and deserves further study
- This trial P02978 is designed to determine whether Lonafarnib can improve patient outcomes in MDS

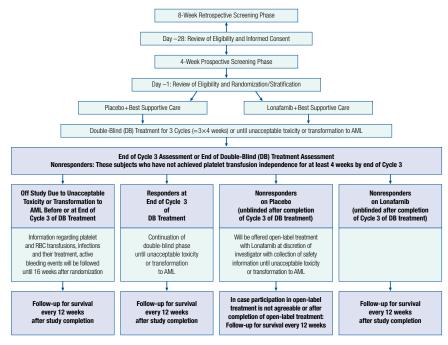
Key Eligibility Criteria

 Platelet transfusion-dependent MDS or CMML patients with or without anemia diagnosed with de novo disease as confirmed by bone marrow aspirate

Additional Eligibility Criteria

- Diagnosed MDS as classified by the French-American-British Classification (FAB) and defined as refractory anemia (RA), refractory anemia with ringed sideroblasts (RARS), refractory anemia with excess blasts (RAEB), and refractory anemia with excess blasts in transformation (RAEB-T), or chronic myelomonocytic leukemia (CMML)
- . No prior therapy with farnesyl transferase inhibitors
- No current therapy with any drugs for the treatment of MDS/CMML other than best supportive care within 12 weeks prior to randomization
- ECOG performance status 0 to 2
- Sexually active women of childbearing age will need to use adequate birth control methods while in the study and will be required to maintain this method throughout the study

P02978 Schema



About Me MDS Foundation: The MDS Foundation is a publicly supported, multissciplinary, international organization devoted to the prevention, restament, and study of MDS. The Foundation has conducted international symposias and lists established an international information network that provides patients with sole tents of the prevention, restament, and study of MDS. The Foundation has information about new research and treatment options. The Foundation also provides educational support to both physicians and patients. For more information about the MDS Foundation, visit waves rest-frontierion or or

Patient enrollment needed. For more information please call 1-888-813-1260 (Outside the US: 609-298-7741) or visit www.mds-foundation.org.



Schering-Plough is the sponsor of this trial. This ad was supported by a grant from Schering-Plough.

Clinical Research Trial For An Oral, At-Home Treatment Option

Learn More About P02978

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS. In the current clinical research trial, all patients will receive therapy with Lonafarnib, an investigational drug that is being evaluated for treating patients with MDS or CMML who have been regularly receiving at least 1 and not more than 8 platelet transfusions every 4 weeks. The medicine is taken by mouth at home, and although patients will be monitored closely, routine hospital stays are not required.

About the MDS Foundation: The MDS Foundation is a publicly supported, multidisciplinary, international organization devoted to the prevention, treatment, and study of MDS. The Foundation has conducted international symposia and has established an international information network that provides patients with referrals to the MDS Foundation's Centers of Excellence worldwide, contact names for available programs, and information about new research and treatment options. The Foundation also provides educational support to both physicians and patients.

For more information about clinical trials with Lonafarnib, call the MDS Foundation at 1-888-813-1260 (outside the US 609-298-7741)

Talk to your doctor to decide if this trial is suitable for you.

(Clinical trial site list on next page)



Schering-Plough has provided the MDS Foundation with an educational grant to support the Foundation's work.

Lonafarnib Clinical Trial Site List (at date of publication)

UNITED STATES

Alvin and Luis Lapidus Cancer Institute

Baltimore, MD Stephen Noga, MD

University of Minnesota

Minneapolis, MN *Mark Reding, MD*

Georgia Cancer Specialists

Tucker, GA Mansoor Saleh, MD

New York Presbyterian Hospital

New York, NY Eric Feldman, MD

New York Medical College

Valhalla, NY Karen Seiter, MD

Bethesda Research Center

Boynton Beach, FL Roger Brito, MD

University of Massachusetts Medical Center

Worcester, MA Azra Raza, MD

Thank You to Our Pharmaceutical Supporters

We would like to thank our pharmaceutical supporters for their commitment to the Foundation and its work. They have contributed in the form of educational grants, which maintains not only this newsletter but also the development of the MDS homepage on the World Wide Web, the Center of Excellence program, continuing medical education programs, the Patient Registry, and the dissemination of patient information.

University of Texas Southwestern Medical Center

Dallas, TX

Robert Collins, MD

James A. Haley Veterans Hospital

Tampa, FL Hussain Saba, MD

University of South California, Norris Cancer Center

Los Angeles, CA Dan Douer, MD

Mayo Clinic Hospital

Phoenix, AZ

James Slack, MD

Scripps Cancer Center

La Jolla, CA James Mason, MD

CANADA / LATIN AMERICA

Canada

Cross Cancer Institute

Edmonton, Alberta *Robert Turner, MD*

Sunnybrook Regional Cancer Center

Toronto, Ontario Rena Buckstein, MD

Princess Margaret Hospital

Toronto, Ontario

Andre Claudius Schuh, MD

Colombia

Fundacion Santa Fe de Bogota

Bogota, Colombia

Monica Duarte Romero, MD

Instituto de Cancerologica SA

Medellin, Colombia *Amado Karduss, MD*

Hospital Militar Central

Bogota, Colombia Benjamin Ospino, MD

Cardio Diagnostico SA

Barranquilla, Colombia Miguel Urina, ME

Ecuador

Hospital Carlos Andrade Marin

Quito, Ecuador Jose Paez, MD

Hospital SOLCA Guayaquil

Guayaquil, Ecuador Bella Maldonado, MD

Cruz Rojo Ecuatoriana

Quito, Ecuador Juan Sghirla, MD

El Salvador

Hospital Nacional Rosales

San Salvador, El Salvador Hector Valencia, MD

Peru

Hospital Nacional Edgardo Rebaglianti

Jesus Maria, Peru Juan Navarro, MD

Puerto Rico

Doctors Cancer Center

Manati, Puerto Rico Kenel Fernandez-Barbosa, MD

San Juan Hospital

San Juan, Puerto Rico Luis Baez-Diaz, MD

San Juan VA Medical Center

San Juan, Puerto William Caceres, MD

EUROPE

Austria

University Clinic of Vienna

Vienna, Austria Peter Valent, MD

Hanusch Hospital of Vienna

Vienna, Austria Thomas Noesslinger, MD Michael Pfeilstoecker, MD

Czech Republic

Institute of Hematology

Prague, Czech Republic Jaroslav Cermak, MD

University Hospital Olomouc

Olomouc, Czech Republic Jana Vondrakova, MD

Germany

St. Johannes Hospital

Duisburg, Germany

Aristoteles Giagounidis, MD

Heinrich-Heine Universitaet

Düsseldorf, Germany *Ulrich Germing, MD*

Universitätklinikum Göttingen

Göttingen, Germany Detlef Haase, MD

Medical School Muenster

Muenster, Germany
Wolfgang E. Berdel, MD

University Hospital Essen

Essen, Germany
Ulrich Duehrsen, MD

Italy

Policlinico Tor Vergata

Roma, Italy
Sergio Amadori, MD

ASL 4 Prato

Prato, Italy

Angelo DiLeo, MD

IRCCS, Casa Sollievo della Sofferenza

Giovanni Rotando, Italy *Pellegrino Musto, MD*

Spain

Hospital Universitario

Salamanca, Spain Consuelo Del Canizo, MD

The MDS Foundation opens its EU Office!

Sophie Wintrich European Patient Liaison Officer The MDS Foundation

I'm delighted to join the MDS Foundation in the capacity of European Patient Liaison Officer. My position is made possible through a grant from the MDS Foundation and additional support from King's College London.

I was born in France, grew up in Germany, studied languages in Paris and gained an MA as a translator at the University of Surrey in the UK. In 1994, my multi-lingual background (French, German and Italian) led me to work for the international medical market research company Fieldwork International/Synovate Group based in London. I initially worked there as an interviewer, then as a Project Coordinator and finally as Project Manager. I quickly developed a specific and keen interest for patient research work and in 2001 started setting up the Patient Research Department within Fieldwork International. Market research projects that I managed included Breast Cancer, MS, Diabetes, Alzheimer's Disease, AMD, Hemophilia, MDS, Growth Hormones and often involved cooperation from various patient support groups. My interests include traveling and psychotherapy.

I started working for the MDS Foundation in August 2007 and I'm enjoying every minute of it. If I can be of assistance, please contact me at:

The Rayne Institute, Denmark Hill Campus, 123 Coldharbour Lane, London SE5 9NU, UK, Tel +44 20 7848 5804

Email: swintrich@mds-foundation.org.

I look forward to supporting the work of the Foundation in Europe, the United Kingdom, and emerging European nations!



Meet the European Patient Liaison: Sophie Wintrich

MDS White Paper Available Through MDS Foundation

This MDS White Paper discusses comparative data and the potential clinical benefits of treatments that are either approved by the U.S. FDA or the EMEA or are under consideration by these bodies. This paper and a subsequent peerreview manuscript will hopefully assist physicians in matching patients with treatment. Coupled with the Foundation's other endeavors we hope to impact the care that is available to patients around the world. To download your free pdf copy, visit our website www.mds-foundation.org or, if you prefer, call 800-MDS-0839 to request a hard copy.

Educational Resources

The Foundation Resource Center is Now Online!

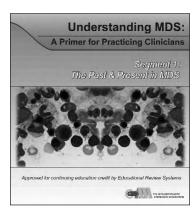
This educational center is designed to provide clinicians, researchers, and other healthcare professionals with a comprehensive source for the latest information and educational programming on the myelodysplastic syndromes.

In the Conference section of our website you can view materials presented at MDS conferences or register for upcoming MDS-related symposia.

Understanding MDS: A Primer for Practicing Clinicians

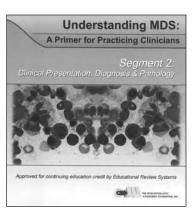
Visit **www.mds-foundation.org** and click on The MDS Foundation Resource Center to take advantage of this comprehensive program, and other informative programs coming soon, designed to provide you with tools and information that will assist you in administering the best care to your patients.

Written programs are available in Spanish, French, Italian, German and Japanese.



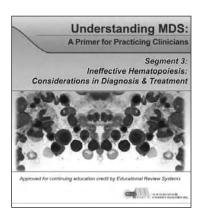
Segment 1: The Past and Present In MDS

Segment 1 provides insight into the history of MDS, development of the MDS classification and prognostic systems, and a glimpse into the future of MDS diagnosis, research and treatment.



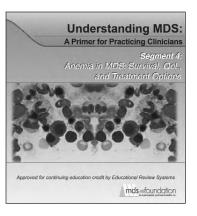
Segment 2: Clinical Presentation, Diagnosis & Pathology

Segment 2 provides insight into the clinical picture of adult and pediatric MDS, primary and secondary MDS, FAB and WHO Classification system, and rationale for the proposed MDS pediatric classification system.



Segment 3: Ineffective Hematopoiesis: Considerations in Diagnosis and Treatment

Segment 3 provides insight into the pathogenic mechanisms that contribute to the development of MDS, including the altered bone marrow microenvironment of MDS in terms of cells, cytokines, growth factors, receptors, and microvasculature; dyserythropoiesis in MDS, and therapeutic targets and approved drugs for the treatment of MDS.



Segment 4: Anemia in MDS: Survival, QoL, and Treatment Options

COMING SOON!

This multi-segment program will allow participants to choose the segments that interest them and to learn at their own pace. Segments may be completed via a written program, on-line in our technologically advanced MDS Foundation Educational Center, or via CD-ROM on their personal computer.

The program is approved for 1 hour of CME credit upon completion. There is no charge for this educational activity.

The Myelodysplastic Syndromes Foundation strives to serve as an effective conduit for information regarding the most updated treatment options, clinical studies, referrals to Centers of Excellence, and other information concerning MDS. Please bookmark our site, www.mds-foundation.org, and check back frequently for new, informative programs.



Genzyme has provided the MDS Foundation with an educational grant to support the Foundation's work.

Help the Foundation and Buy Your MDS Textbooks From Us!



Myelodysplastic Syndromes: Clinical and Biological Advances

Peter L. Greenberg, MD Stanford University Medical Center

Hardback, Nov. 2005/320 pp., illus. ISBN: 0521496683/\$125.00** Cambridge University press

As the current major comprehensive reference on all aspects of the clinical classification underlying pathogenetic mechanisms and treatment of the myelodysplastic syndromes, Myelodysplastic Syndromes stands out as the definitive text on the genetics, pathophysiology, and clinical management of this wide range of syndromes. Authored by international experts, this book provides a state-of-the-art update of the current status and recent advances in the field. The chapters cover all aspects of the myelodysplastic syndromes, from an in-depth analysis of the multifactorial nature of this disease, including a careful assessment of stromal, immunological and stem cell abnormalities, to a review of recent molecular and cytogenetic discoveries and insights.

This book will be a valuable resource to clinicians and researchers who wish to learn more about myelodysplastic syndromes.



Myelodysplastic
Syndromes & Secondary
Acute Myelogenous
Leukemia: Directions
for the New Millennium
(Cancer Treatment
and Research)

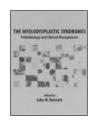
Edited by:

Azra Raza, MD; Suneel D. Mundle, PhD

June 2001/278 pp., illus. ISBN: 0792373660/\$198.00** Springer Science + Business Media, Inc.

Myelodysplastic syndromes are to the bone marrow what pneumonia is to the lungs; the response of an organ to a variety of etiologic insults like aging, toxic exposure, infections and auto-immunity. Among

infectious causes alone, pneumonia could be the result of a variety of possible pathogens including bacterial, viral, tuberculous or fungal agents. Similarly, MDS cannot be treated as a single disease. Attempts to harness the inherent complexity of MDS by devising "classifications" which group the various syndromes as one disease is as misguided as saying that a pneumonia is not infectious because it did not respond to antibiotics. Progress in the field will occur faster when we re-analyze this premise. Therefore, until a clearer picture of the disease emerges it is best to treat each of the MDS syndromes as a separate entity. Having no classification is better than a misleading one. This book is our attempt to define the most crucial questions related to MDS that need to be addressed immediately through logic, analysis and rigorous experimentation. If the emerging problems appear daunting, then instead of being overwhelmed by them, we should follow the advice of the great 20th century thinker Antonio Gramsci, "pessimism of the intellect must be faced with the optimism of will".



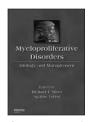
The Myelodysplastic Syndromes Pathobiology and Clinical Management (Basic and Clinical Oncology Series/27)

Edited by:

John M. Bennett, MD James P. Wilmot Cancer Center of the University of Rochester, Rochester, New York, U.S.A.

May 2002/528 pp., illus. ISBN: 0-8247-0782-6/\$165.00** CRC Press. 800-272-7737

This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse environmental and genetic factors, and efficient modalities of supportive care that improve patient survival and enhance quality of life.



Myeloproliferative Disorders: Biology and Management

Edited by:

Richard T. Silver, MD; Ayalew Tefferi, MD

October 2007/240 pp., illus. ISBN: 9781420061628/\$161.96** CRC Press: 800-272-7737

Myeloproliferative disorders, written by international renowned experts in the field, examines:

- New and developing diagnostic protocols and algorithms and supportive care regimens
- The evolution and classification of recent myeloproliferative disorders
- Advancements and the implications arising from clinical care and practice
- The activating JAK2V617F developed in a chapter by top experts
- The overlap between myeloproliferative disorders and myelodysplastic syndromes
- The importance of histopathology and cytogenetics on understanding these diseases

With the recent discovery of JAK2 mutations in myeloproliferative disorders, medical science has taken a revolutionary stride forward toward understanding the pathogenesis of these diseases. This new advancement translates not only to a more rapid and reliable diagnosis, but also allows groundbreaking research into the development of new therapeutics. Written in an easy-to-follow text myeloproliferative disorders gives the practicing clinician a single source answer to classification, diagnosis, management, and recent advances in this disorder.

**All prices are in US dollars.

To order call MDS Foundation at 1-800-MDS-0839. TERMS OF THE OFFER:

All individual orders must be prepaid by check or money order or charged on Visa, Mastercard, or AmEx). Canadian residents, please add 7% GST. Residents of CA and NY, please add local sales tax. Shipping and handling charges for North America are \$6.00 for the first book and \$1.75 for each additional book. Outside North America (only credit card orders accepted) — \$9.00 for first book; \$5.00 for each additional book.

Highlights of Latest Literature in MDS

Listed below are citations of some new publications relevant to MDS (pathogenesis, clinical characterization, management, etc.). To access the complete article log on to www.pubmed.gov.

MDS OVERVIEW AND PERSPECTIVES:

1. Mundle S. Erythropoiesis-stimulating agents versus RBC transfusion in MDS: comparison of long-term outcomes. *Future Oncol.* 2007;3:397–403.

The article provides perspective on deleterious effects of chronic RBC transfusions and shows that ESA treatment provides efficacious alternative with favorable safety profile in low/int-1 risk MDS.

DIAGNOSIS AND PROGNOSIS:

2. Demirkan F et al. The clinical, haematological and morphological profile of patients with myelodysplastic syndromes: A single institution experience from Turkey. *Leukemia Lymphoma*. 2007;48:1372–1378.

The study confirms the difference in survival and leukemia free survival between patients with RA/RARS vs. RCMD/RCMD-RS. Additionally the multivariate analysis revealed negative impact of Hb < 10g/dL, neutrophil $< 0.5 \times 10^9$ and platelets $< 50 \times 10^9$ on survival.

myelodysplastic syndromes. Leuk Res. 2007; May 14 [Epub ahead of print].

A population-based cancer registry study for incidence of MDS within the state of Connecticut, USA, shows nearly 3 times higher incidence of MDS than expected near Western border of the

state. This is the first evidence of

clustering in incidence of MDS.

3. Ma X et al. Clustering in the incidence of

4. Takatoku M et al. Retrospective nationwide survey of Japanese patients with transfusion-dependent MDS and aplastic anemia highlights the negative impact of iron overload on morbidity/ mortality. *Eur J Haematol*. 2007;78: 487–497.

The study highlights deleterious effects of chronic RBC transfusions and suggests that serum ferritin levels exceeding 1000 ng/mL could cause end-organ damage (cardiac and liver toxicity) leading to mortality.

 Kantarjian H et al. The incidence and impact of thrombocytopenia in myelodysplastic syndromes. *Cancer*. 2007;109:1705–1714.

A review of literature showed that prior to any treatment of MDS, a median rate of thrombocytopenia was 65%, which seems to be paralleled by 67% detection rate reported at authors' institution at referral with preponderance seen in Int-2/High risk categories.

TREATMENT:

 Lim ZY et al. Low IPSS score and bone marrow hypocellularity in MDS patients predict hematological responses to antithymocyte globulin. *Leukemia*. 2007;21:1436–1441.

The study identifies a niche for ATG treatment in MDS.

PATHOBIOLOGY:

7. Braun T et al. Differentiating megakaryocytes in myelodysplastic syndromes succumb to mitochondrial derangement without caspase activation. *Apoptosis*. 2007;12:1101–1108.

Purified marrow CD34(+) cells from MDS patients when induced to undergo megakaryocytic differentiation, underwent apoptosis without Caspase 3 activation, but demonstrated mitochondrial apoptotic changes including cytochrome c release. In contrast, matured normal megakaryocytes manifested caspase 3 pathway of apoptosis.

8. Nilsson L et al. The molecular signature of MDS stem cells supports a stem cell origin of 5q- myelodysplastic syndromes. Blood. 2007; July 6 [Epub ahead of print]. The CD34(+) CD38(-) Thy1(+) cells bearing 5q- abnormality specifically

- appear to have elevated expression of BMI1 and down regulation of CEBPA as compared to normal counterparts in MDS patients with 5q- karyotype.
- 9. Pellagatti A et al. Lenalidomide inhibits the malignant clone and up-regulates the SPARC gene mapping to the commonly deleted region in 5q-syndrome patients. *Proc Natl Acad Sci USA*. 2007;104:11406–11411.

The studies shows that lenalidomide specifically inhibited growth of erythroblasts with 5q- karyotype as compared to those without cytogenetic abnormality.

Now Available From The Foundation

We have assembled a listing of insurance and drug reimbursement resources for MDS patients. It is important to know that there is support for those who cannot afford medicine or other healthcare costs. We hope this new resource will be beneficial in helping you with your medical needs.

This guide to assistance programs in the United States is available for download from the Foundation's website or can be ordered in booklet form upon request.



Blood & Marrow Transplant News

Blood & Marrow Transplant Newsletter is published four times annually by BMT InfoNet.

To subscribe, contact:

BMT InfoNet 2900 Skokie Valley Road, Suite B Highland Park, IL 60035

Toll free: 888-597-7674

Tel: 847-433-3313, Fax: 847-433-4599

E-Mail: help@bmtinfonet.org Web: www.bmtinfonet.org

MDS Foundation Publications

Patient Information & Educational Materials Available from The MDS Foundation

- The MDS News
- MDS Essentials: The Foundation's E-Newsletter
- Patient Diary



- Understanding Myelodysplastic Syndromes: A Patient Handbook
- Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients
- Insurance and Reimbursement Resources for MDS Patients
- Emerging Treatment Options for Adult MDS: A Clinical Perspective
- Planned Giving Program:A Guide to Financial Planning
- Your Journal: Learning About Myelodysplastic Syndromes (MDS) Supported by a grant from Celgene Corporation.
- PBS Program (Videotape)
 Healthy Body, Healthy Mind: Learning
 About Myelodysplastic Syndromes
- PBS Program (DVD) Healthy Body, Healthy Mind: A Menace in the Blood
- Understanding Myelodysplastic Syndromes: A Patient Handbook

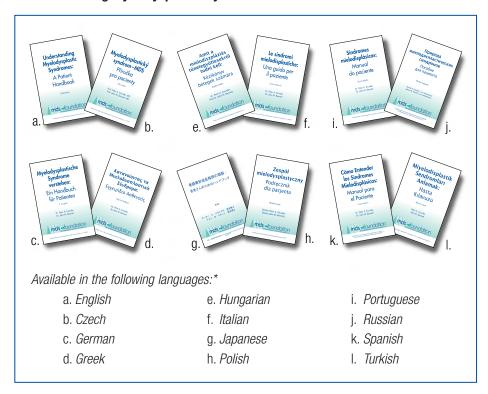
All of these materials are available free of charge from the Foundation.

* The MDS Patient Handbooks will soon be available in the following languages: Arabic, Dutch, Swedish.

The Iron Overload booklets will soon be available in the following languages: *Arabic, Turkish*

MDS Handbooks Now Available in Multiple Languages

■ Understanding Myelodysplastic Syndromes: A Patient Handbook



■ Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients



Contributions to the MDS Foundation

Ways to Support Us

The MDS Foundation is very grateful for the heartfelt support of its donors. Our work as a non-profit organization depends on public funding and we hope that you include us as one of the worthy charities that you support this year. We have enclosed a preaddressed contribution envelope to make it easier. You will receive an MDS Foundation enamel lapel pin in appreciation of your donation.

All donations are tax-deductible.

A Living Endowment

Many families are affected by living with the reality of MDS. There is an extraordinary way to contribute to the MDS Foundation and support our mission of working as a resource for patients, families, and healthcare professionals.

A commitment to donate to the Foundation on occasions of loss, birthdays and anniversary remembrances can be made. Honor your friends or family members on these occasions with a donation, and The MDS Foundation will send an acknowledgment to the recipient, recognizing the occasion.

A Living Endowment donation has been made in honor of:

Jeff and Mei Sze Greene's

Wedding

This donation has been submitted by:

Steve Smotrich and Ros Westlake *Stockton, NJ*

Gifts to the Foundation

The MDS Foundation relies entirely on gifts and membership fees to further its work. We would like to acknowledge the generosity of the following individuals and organizations that have recently provided gifts to the Foundation:

Dr. and Mrs. John M. Bennett

Rochester, NY

Susan J. Ferber

In memory of Dr. Jerome Ferber

New York, NY

Robert J. Weinberg and Rochelle Ostroff-Weinberg

Wynnwood, PA

Dr. Stuart Goldberg

Hackensack, NJ

Dr. Steven D. Gore

Baltimore, MD

Dr. Peter L. Greenberg

Stanford, CA

Dr. Paul M. Nemiroff

ibsonia, PA

Jayne Butler

Warren, NJ

Alfred and Dorothy Harding

Medford, NJ

Amy C. Cavers

via United Way

Benita Thompson

Mt. Laurel, NJ

Charles Robertson

Glen Mills, PA

DEKKER

Boca Raton, FL

Douglas B. Nelson

Stamford, CT

Ed and Muriel Pickard

Highland Beach, FL

Francine Pollack

Naples, FL

Glenn R. Laird

Grants Press, OR

Groov-Pin Corporation

Smithfield, RI

Helen Pearson

Powhatan, VA

John Cazier

Corona Del Mar, CA

Joseph Artuso

Berwyn, PA

Madhavbhai B. Patel

San Francisco, CA

Margaret T. Yamato

Honolulu, HI

Marguerite L. Downer

Carmel, CA

Myrna Pearlman

Longboat Key, FL

Quin Hauss

San Luis Obispo, CA

Richard and Julita Christian

Alexandria, VA

Richard Hatfield

Highlands North, AFRICA

Salustiano Mandia

Madrid, SPAIN

Samuel T. Arnold, Jr.

Pennington, NJ

Geoff and Sandy Goldworm

Cherry Hill, NJ

Shirley Peterfreund

Delray Beach, FL

Stacey L. Tomasi

Royersford, PA

Stuart Goldberg

Hackensack, NJ

Sunnybrook Health Science Centre

Toronto, Ontario, Canada

William O'Keefe

Providence Forge, VA

William Shulevitz

New York, NY

In Memorium

A memorial fund has been established in the name of

Mr. Lawrence Raymond Abbey

Donations have been made in Mr. Abbey's memory by:

Angels in the Outfield Donna Bobit Sun City West, AZ Sun City West, AZ Kenneth and Paula Dudiak John Reed Battle Creek, MI Sawver, MI

Dave and Sandra Nuese South Lake, TX

A memorial fund has been established in the name of Mr. John Anderholm

Donations have been made in Mr. Anderholm's memory by:

Hazel Anderholm, Walnut Creek, CA

A memorial fund has been established in the name of Mr. Paul Katao Aono

Donations have been made in Mr. Aono's memory by:

Elaine J. Shiozawa, Honolulu, HI

A memorial fund has been established in the name of Mr. John Armstrong

Donations have been made in Mr. Armstrong's memory by:

Kenyon & Kenyon LLP, New York, NY

A memorial fund has been established in the name of Ms. Lynn Bernstein

Donations have been made in Ms. Bernstein's memory by:

The Young Family Allen and Sugie Kovin Highland Park, IL Sharon MA Gregory D. Jones Anita Klauber Pueblo, CO Highland Park II The Board and Residents Bernie and Patti Burton of The Manors of Fvanston II Highland Park Joe Bernstein Highland Park, IL Highland, IL Judy Klarfeld Michael and Ruth Smilg Winnetka, IL Deerfield, IL

A memorial fund has been established in the name of Mr. Benjamin Berreth

Donations have been made in Mr. Berreth's memory by:

Irma R. Berreth, Surprise, AZ

A memorial fund has been established in the name of Ms. Marianne L. Bloschies

Donations have been made in Ms. Bloschies's memory by:

Alison Johnson, Burlington, VT

A memorial fund has been established in the name of Mr. Stuart Bush

Donations have been made in Mr. Bush's memory by:

Joel Hageman Larry and Doris Stromer Berryville, AR Hastings, NF Lila Dovel Mountain Home, AR

A memorial fund has been established in the name of

Mr. Bertram Cameron

Donations have been made in Mr. Cameron's memory by:

Sam and Karen Consiglio Wilma D. Wood Coconut Creek, FL Ruskin, FL Larry Kades Syd and Anita Berkey Pittsburgh, PA Blue Bell. PA

A memorial fund has been established in the name of Mr. Alcide Canzian

Donations have been made in Mr. Canzian's memory by:

The US Naval Observatory. Flagstaff Station Flagstaff, AZ

L-3 Communications Corporation Brashear Div. Pittsburgh, PA Mark Guzan and Family Pittshurah PA

A memorial fund has been established in the name of **Captain Norman Carpenter**

Donations have been made in Capt. Carpenter's memory by:

Ed and Pat Meyers Audubon, PA

John & Frances Greenbaum Bala Cynwyd, PA

Paul and Pam Strahm Audubon, PA

Littleton and Susan Roberts Audubon, PA

A memorial fund has been established in the name of **Dr. Paul Cherkasky**

Donations have been made in Dr. Cherkasky's memory by:

Harold and Rhea Feinberg Rochester, NY

Charlie & Mickey Hollander West Islip, NY

Bob and Barbara Levine Coconut Creek, FL

Bob and Linda Yawman Fairport, NY

Erminia Properzi East Rochester. NY

Agata Piccirilli Penfield, NY

Lillian DiPrima and Family

Rochester, NY

Barry Bordwell Penfield, NY

Dorothy M. Rossi Rochester NY The Dodson Family

Pittsford, NY Edwin and Patricia Mindlin

Rochester, NY

Mel and Cindy Gurell Rochester, NY Mary E. Palumbo

Rochester, NY Joe and Caroline Bailey

Rochester, NY Marcy Adams

Fairport, NY Ron & Sara Freeling and Family Rochester, NY

Dr. and Mrs. Lawrence and Merle Markus Penfield NY

Richard & Barbara Mahonev Rochester, NY

David and Susan Senise Pittsford, NY

Margot Schuler Webster, NY

Jack and Annette Naughton Rochester, NY

Esther Getto Mechanicsburg, PA Stan & Marge Prewasnicak Rochester, NY Tara A. Shelton

Rochester, NY

George and Mary Dastyck Tucson, AZ

Gastroenterology Group of Rochester, LLP Rochester, NY

Richie & Barbara Michaels Rochester, NY

David C. Pettig & Associates, P.C. Pittsford, NY

Catherine Christman Rochester, NY Lee and Ellen Little

Pittsford, NY

Donald and Barbara Willer Webster NY

Jack and Sonya Presberg Rochester, NY

Jerome & Barbara Caplan Henrietta. NY

State Road School Sunshine Committee Wehster NY Glenna Blitz

Webster, NY

Dr. Paul Cherkasky (continued)

Emma Bushey Kerry and Patty Kenney Rochester, NY Fairport, NY Lyle Bassage Marilyn Reich Walworth, NY Tamarac, FL Mort and Bunny Skirboll Jim, Peggy Best and Family Rochester, NY Rochester, NY Shervl J. Leupold

Norman and Judie Reich Penfield NY Rochester, NY University Medical Imaging Charles DiPrima Rochester, NY Rochester, NY Pamela Robinson San Francisco, CA The Feeley Family Fairport, NY Helen M. Senzel

Rochester, NY Saul and Helen Presberg Rochester NY John and June Addino

Webster, NY Maria Rendziak Rochester, NY Marvin & Marilyn Horowitz Bruce and Mary Vickers Rochester, NY

Rochester, NY Charles and Betty Michalko Pittsford, NY Donna R. Weinstein New York, NY Ron and Jill Malley Webster, NY Lisa Aldridge Rochester, NY The Jakahi Family Pearl City, HI Wayne A. Shelton Albert & Goldie Boberman Rochester NY Sandra F. Gordon Pembroke Pines, FL

A memorial fund has been established in the name of Mr. Edgar Cote

Bavside, NY

Donations have been made in Mr. Cote's memory by:

Claire Bouffard Robert Hodge Biddeford, ME Biddeford, ME John and Stella Woodbury Richard Moore Saco, ME Biddeford, ME Dolly Cote Maurice Labrecque Saco, ME Saco, ME John and Stella Woodbury Marc Beauregard Saco, ME Saco. ME Roland Regis Claire Bouffard Biddeford, ME Saco, ME

Richard and Beverly Libby Shaun and Lisa Sullivan

Saco, ME Saco, ME Doris Mondor Rev. Raymond D. Auger Biddeford, ME Boynton Beach, FL Albert Deshaies John J. Harvey Saco. MF Riddeford MF Raymond Nadeau John and Alyce Burns

Lowell, MA Biddeford, MF Joseph Doherty The Selker Family Biddeford, ME Cincinnati, OH

A memorial fund has been established in the name of Ms. Ana Josefa Cordova

Donations have been made in Ms. Cordova's memory by:

Kidde Fire Trainers Inc. Montvale N.I.

A memorial fund has been established in the name of Mrs. Delores Coughennower

Donations have been made in Mrs. Coughennower's memory by:

Joe. Carol Tucker & Family Oak Forest, IL

Thomas & Christine Tucker Homer Glen II

Joseph and Betty Tucker

Oak Lawn, IL

A memorial fund has been established in the name of Mr. David K. Cowser

Donations have been made in Mr. Cowser's memory by:

Joseph and Mary Smyrl Oak Ridge, TN W.C. and Julia Hoppe Oak Ridge, TN Robin Kincaid Las Vegas, NV

Don and Jeanne Pemberton Germantown, TN

William and Margaret Pryor Oak Ridge, TN

Kenric Ashe & Angela Holt Portland, OR Helen Kapral

Oak Ridge, TN

Donald A. Gardiner

Oak Ridge, TN

Sydney and Rebecca Ball Oak Ridge, TN Richard B. Schappel

Oak Ridge, TN

Dr. and Mrs. Rex and Johnnie Amonette *Memphis, TN*

Don & Jeanne Pemberton Germantown, TN

Dr. and Mrs. Frank and Martha Witherspoon *Memphis, TN* Karns Bridge Friends

Knoxville, TN

Dr. and Mrs. Dennis and Joanna Higdon *Memphis, TN* Jane H. Adams

Oak Ridge, TN
Fred and Charlotte Hodges
Memphis, TN

L. Dean & Virginia Eyman Oak Ridge, TN Helga Gerstner-Player Oak Ridge, TN

A memorial fund has been established in the name of Ms. Sally Cvrkel

Donations have been made in Ms. Cvrkel's memory by:

Linda Cyrkel, Annandale, VA

A memorial fund has been established in the name of Ms. Raffaella Vezzosi da tutti i nipoti

Donations have been made in Ms. Vezzosi's memory by:

Alessandro Francesco Degl Innocenti Galligani Montecatini Terme. ITALY

A memorial fund has been established in the name of Mrs. Mary Ellen Davies

Donations have been made in Mrs. Davies' memory by:

Donald and Jane Koontz, Sarasota, FL

A memorial fund has been established in the name of Mr. Alvin E. Delger

Donations have been made in Mr. Delger's memory by:

Jo Ann, Carroll & Levi Catanese New Orleans, LA Luka and Judith Cvitanovic Gretna, LA

Philip and Gayle Fielding Slidell, LA

Charles and Edna Richard Gonzalez, LA

Marion W. Buhrer

Louis Szabo Terrytown, LA

Jock & Penny Hopkins and Family Kiawah Island, SC

Kenny and Denise Martin Slidell, LA

Joyce Mole Gretna, LA

Deb, Phil & Jacques Boudreaux New Orleans, LA

A memorial fund has been established in the name of Mr. Donald Derrick

Donations have been made in Mr. Derrick's memory by:

Harry and Agi Devlin Flanders, NJ Richard and Shari Palmer Fair Haven, NJ Jose and Esther Quinones

Newark, NJ

Joe and Kathy Schwab Flanders, NJ

Margaret I. Hemmer Hallmark Capital Mgmt, Inc. *Wayne, NJ*

Thomas & Ann Marie Harrison Chatham, NJ

Suzanne Fleischman Memorial Fund for Patient Advocacy

A fund has been established by the MDS Foundation in memory of Suzanne Fleischman. Contributions may be sent to the Foundation with a notation designating the Suzanne Fleischman Memorial Fund for Patient Advocacy.

A new donation has been made by: **Edward Fleischman,** *Prescott, Arizona*

A memorial fund has been established in the name of Mr. Paul Laurice Desmarais

Donations have been made in Mr. Desmarais' memory by:

David McGrew Thomas and Ann Lowden Alexandria, VA Sterling, VA

Patricia A. Bloomfield Chevy Chase, MD

A memorial fund has been established in the name of Mr. Bruce Dixon

Donations have been made in Mr. Dixon's memory by:

FGD Project Team Sara Marie Baldi Reliant Energy Inc. Pittsburgh, PA Cheswick, PA

A memorial fund has been established in the name of Mr. Edward R. Doerfler

Donations have been made in Mr Doerfler's memory by:

Harry J. McGovern, Jr., LaFace & McGovern Associates, Inc. *Bethel Park PA*

A memorial fund has been established in the name of Mr. Bernard Dounn

Donations have been made in Mr. Dounn's memory by:

Sally Harvey
Sheldon, SC

Pearl Lucas and Family
Pompano Beach, FL

Broad River Elementary
Beaufort, SC

George Hartman
and Sylvia Dounn
Melbourne Beach, FL

A memorial fund has been established in the name of Mrs. Elaine Ellerstein

Donations have been made in Mrs. Ellerstein's memory by:

Dr. Stuart Ellerstein and Family, Princeton, NJ

A memorial fund has been established in the name of Dr. Temple Elliott

Donations have been made in Dr Elliott's memory by:

Dr. and Mrs. William Mark and Vicki Freeman Wallace, Amarillo, TX Texhoma, Oklahoma

A memorial fund has been established in the name of Ms. Mette Emily Finch

Donations have been made in Ms. Finch's memory by: Dr. and Mrs. Cara and Sid Berger, *Ft. Lee, NJ*

A memorial fund has been established in the name of Mr. Sam Friedman

Donations have been made in Mr. Friedman's memory by:

Wm. Mark Friedman, Litchfield, CT

A memorial fund has been established in the name of Mr. Glen Edward Gardner

Donations have been made in Mr. Gardner's memory by:

Martha Hart Mary Ann Checkon Tucson AZ Tucson AZ Mildred Garrett The Frederick Family Huntington Beach, CA Rosemead CA Bill and Claudia Palleva Jeannine Waggoner Cerritos, CA Huntington Beach, CA Charles and Lucille Vestal Mr. and Mrs. John Deka Long Beach, CA Westminster, CA Patricia H. Williams Richard and Audrey Deaton Torrance, CA Huntington Beach, CA Warren and Arleen Olsen Hank and Nancy Becker Fountain Valley, CA Endicott NY Charlotte Wagner Donald Rabe Westminster CA Huntington Beach, CA Gerald R. Goudreau Harry and Carolyn Landon

Fort Wright, KY

Velda L. King

Huntington Beach, CA

Jeanene Landon

Burlingame, CA

Rosemarie Kendig

Fountain Valley, CA

Phoenix, AZ

Layne Goudreau

Sun City, AZ

Leno and Phyllis Berg

Huntington Beach, CA

The Cowie Family

Huntington Beach, CA

A memorial fund has been established in the name of Mr. Joseph Gieger

Donations have been made in Mr. Gieger's memory by:

Salli-Ann Mullan

East Hanover, NJ

Walter & Mildred Strohmaier

East Hanover, NJ

John and Meg Campoli

Cresskill, NJ

Cresskill, NJ

A memorial fund has been established in the name of Mrs. Voncille Gilruth

Donations have been made in Mrs. Gilruth's memory by:

Martin J. Goodale David and Robin Anderson Shorewood, IL New Lenox, IL
David and Rita Saxon Louis and Nancy Duay Shorewood, IL
Shorewood, IL

Jenny A. Potanos, MA CCC SLP Michael and Jolene Canady Wheaton. II Minooka. II

Stanley J. Rousonelos

James and Ingrid Haase

Joliet, IL Morris, IL
Frank S. Dickey, Jr. Dawn K. Anderson
Braceville, IL El Paso, IL

Braceville, IL El Paso, IL
Ralph and Patricia Bryson Robert & Sandra McLurkin

Joliet, IL Sumter, SC
Saul and Edna Brass Leflain Support Group
Joliet, IL Palmetto, FL

Donald & Joyce Lockwood Michael Calandro Shorewood, IL

A memorial fund has been established in the name of Ms. Ann Elizabeth Graham

Donations have been made in Ms. Graham's memory by:

Pamela J. Peterson Transatlantic Brides and Orange Park, FL Parents Association

Jacksonville, FL

A memorial fund has been established in the name of Ms. Elena Guinn

Donations have been made in Ms. Guinn's memory by:

Eddie and Lydia Casillas JoAnn George Chandler AZ Chandler, AZ

A memorial fund has been established in the name of Ms. Claudia Hagen

Donations have been made in Ms. Hagen's memory by:

Walter and Mildred Strohmaier, East Hanover, NJ

A memorial fund has been established in the name of Mr. Andrew E. Helmich, Sr.

Donations have been made in Mr. Helmich's memory by:

Associated Oral and Linda Lunzer Maxillofac Little Canada, MN Fridley, MN Peter and Judy Obermeyer Paul and Mary Hobday Fdina MN Plymouth, MN Judith Olson Elizabeth Heaman Minneapolis, MN Scandia, MN Stephen and Wendy Osman David and Jeanne Anderson

Minneapolis, MN Minneapolis, MN Marcos and Barbara Pinto Mark M. Dale Plymouth. MN

Buffalo, MN John and Cleone Sherman Diane R. Bangerter Hernando, FL Hopkins, MN Sharon Stevens

Larry and Carla Carlson Barbara and Bill Whitmore Plymouth, MN Maple Grove, MN Dr. and Mrs. Melvin Dale Diane & Harry Strandberg, Plymouth, MN and Robert Ware

Maple Grove, MN Brian DeVoe Minnetonka, MN Julie Wicklund Schaumburg, IL Minneapolis, MN Norine M. Sickel Julie Hoff Minnetonka, MN Nancy Helmich and Family

Minneapolis, MN Pamela Hufstader, Minnesota Heidi Helmich Legal Assistant Institute Denmark, EUROPE Minnetonka, MN

Donald and Ann Johnson Emily Her Minneapolis, MN Chicago, IL

A memorial fund has been established in the name of Mrs. Audrey Higdon

Donations have been made in Mrs. Higdon's memory by:

Doris M. Napoli Lisa Napoli Rockville, MD Grasonville, MD Brad and Donna Napoli Josh and Sandy Rivlin Silver Spring, MD

A memorial fund has been established in the name of Mr. Joseph Hodess

Donations have been made in Mr. Hodess' memory by:

Ruth Lublin, Bryn Mawr, PA

A memorial fund has been established in the name of Mr. Kenneth D. Hoefel

Donations have been made in Mr. Hoefel's memory by:

Marjorie K. Sager, Venice, FL

A memorial fund has been established in the name of Mr. Masami Joe Honda

Donations have been made in Mr. Honda's memory by:

Lapp, Fatch, Myers Olivia Tonascia & Gallagher Santa Maria, CA Santa Maria, CA Louise Tonascia Lanini's Plumbing Repair Santa Maria, CA Santa Maria, CA Michael, Cindy, Victor and Grant Oshita Sacramento, CA

A memorial fund has been established in the name of Mr. Donald Hunt

Donations have been made in Mr Hunt's memory by:

Kevin and Veronica Hunt, Verona, NJ

A memorial fund has been established in the name of Ms. Esther Lutsky Jewler

Donations have been made in Ms. Jewler's memory by:

Chuck and Marcia Wesoky Richard and Joan Rind Mrs. Lenore Jewler Silver Spring, MD New York NY Charles and Irene Rosen Blanche E. Kramer Chevy Chase, MD Silver Springs, MD Sheila Footer Irwin and Fay Gold Chevy Chase, MD Laurel, MD

A memorial fund has been established in the name of Mr. John D. Jov

Donations have been made in Mr. Joy's memory by:

John E. Wickert Frederick P. Wickert Raytown, MD Raytown, MD

A memorial fund has been established in the name of Ms. Virginia M. Kaspar

Donations have been made in Ms. Kaspar's memory by:

Eric and Gail Scheithauer Mary Trinity Reeks Fort Wayne, IN Marilyn Hennig Bloomingdale, II.

A memorial fund has been established in the name of Mr. Joseph Kavich

Donations have been made in Mr. Kavich's memory by:

Jeanmarie Wheeler, Channahon, IL

A memorial fund has been established in the name of Ms. Ann Keith

Donations have been made in Ms. Keith's memory by:

Angelo and Rose Staikos, Hazlet, NJ

Scott Depot, WV

A memorial fund has been established in the name of Mr. Thomas Edward Kennell

Donations have been made in Mr. Kennell's memory by:

Henry Richardson **Dolores Smith** Blacklick, OH Charleston, WV Ronald and Angela Dowd Ron and Sue Eisinger New York, NY Charleston, WV John and Janet Gagnon Vonn and Anne Carroll Charleston WV Charleston WV James and Martha Ranson Harvey & Norma Hammons

Mr. Thomas Edward Kennell (continued)

Kathleen Simpson and

Dixon Hughes PLLC

Charleston, WV

Lostant, II

Peru, IL

Catherine Kennell

Mr. & Mrs. Richard Vastnik

Mike Gilzow Gandeeville, AR

Tom and Dreamma Guinn Charleston WV Dr. and Mrs. David and Barbara Bryant S. Charleston, WV Henry and Sandra Huff

Charleston, WV John and Jessica Flaherty

Destrehan, LA Kay P. Vealey Charleston, WV

Cvril and Veronica Tellis Charleston, WV

Bob and Donna Taylor Scott Depot, WV

A memorial fund has been established in the name of Mr. Ascher Korn

Donations have been made in Mr. Korn's memory by:

Steven Goldstein Jean Fishman New York, NY Franklin Sq., NY

A memorial fund has been established in the name of **Dr. Burton Kraus**

Donations have been made in Dr. Kraus' memory by:

Beth Kraus Weinstein Anita Kraus Somerset, PA Havertown, PA Janice Kraus

A memorial fund has been established in the name of

Mrs. Margaret Krock

Donations have been made in Mrs. Krock's memory by:

Wes, Mary Leigh, Jordan Lee Ann Howarter and No Krock Canton, IL Monkton, MD Rick and Chris Duvendack

Canton, IL

Ed Coleman

Canton, IL

Canton, IL

Canton, II

Canton. IL

Canton, IL

Canton, IL

Paula Wright

Thorburn Enge

Canton, IL

Canton. IL

Melvin Woods

Dr. Ernesto Noche

Bolingbrook, IL

Carole Sandman & Family

Gerald and Ann Henderson

Mike and Sarah Wright

Roberta Graham Orwig

Margaret Wright and

Bonnie Busam Canton, IL Peoria, IL Robert and Melba Orwig

Robert and Joyce Molinari

Oswego, NY Graham Hospital Patient

Pittsburgh, PA

Registration Department Canton, IL

Larry and Joyce Latimer Canton, IL

Kline and Marilyn Laird

Canton, II.

Slick and Jean DeRenzy

Canton II

Bob and Diane Juraco Galesburg, IL

Dr. & Mrs. Jeremy L. Krock

Peoria. IL

Sigma Phi Gamma Sorority

Canton, IL

Robert and B. Joan Linn Peoria, IL

William and Virginia Vasen

Canton, IL

Melvin and Roberta Fletcher

Canton. IL Bill and Colleen Juraco

Canton, II.

Terry and Donna Wignall Mapleton, IL

Charles and Carol Haggerty Canton, IL Robert and Debra Busby

Canton, IL

Francis & Madeline Niehaus

Cheve Coeur, MO

St. Helena IS. SC

A memorial fund has been established in the name of

Mrs. Susan M. Lachut

Donations have been made in Mrs. Lachut's memory by:

Keith Lachut Baton Rouge, LA Joe Miller & John Reardon Buffalo, NY Gerald Lachut Corning, NY Ruairi Powers Stamford, CT John G. Ferris Albion NY

Christ Episcopal Church Lockport, NY Gregory and Stephanie Woods Cicero, NY Wayne and Jane Tylec N. Tonawanda, NY

Dan Fiorini Liverpool, NY John M. Amato Cicero, NY Rob and Nancy Foster Phoenix, AZ

John and Marylynn Wilson Mattydale, NY

Louis and Linda Bregou Brewerton, NY Kristin Bogan

Syracuse, NY Quality Lighting Systems, Inc. Liverpool, NY Michael and Kathleen McBride

Baldwinsville, NY Paul and Sharon Lutheran North Syracuse, NY

Zeller Corporation Rochester, NY

Hubbell Lenoir City, Inc. Lenoir City, TN

Ray and Maureen Dominic Phoenix, NY

Nick and Cheryl Garzia Syracuse, NY James and

Jeanne Rodems Syracuse, NY Ferraz Shawmut Inc. Newburyport, MA

The Gill Family Orchard Park, NY

E-Mon, LLC Langhorne, PA O. M. E. C. A. Syracuse, NY R. F. Peck Co., Inc.

Albany, NY Frederick and Karen Dombrowski

North Tonawanda, NY Troy Belting & Supply Co. Watervliet, NY

Cusick Electrical Sales, Inc. Willow Grove, PA Ridlev Electric Co. Inc.

Syracuse, NY Joev's Brokerage of Syracuse New York, Inc.

Syracuse, NY Hammond Power Solutions, Inc. Barahoo WI

Daniel and Susan Bednarski and Family Liverpool, NY

Steve and Ann Trulin Fnalewood Fl Lesco, Inc.

Minneapolis, MN Hammond Manufacturing

Company Inc. Cheektowaga, NY Consolidated Electrical Distributors. Inc. Colorado Springs, CO

Electro Lines Inc. Syracuse, NY William Kaljeskie North Syracuse, NY Tulimieri Associates Inc. Glastonbury, CT

James and Marcia Elving Ballston Lake, NY City Electric

Syracuse, NY Edward and Nancy Coye Syracuse, NY

Christine A. Woods East Syracuse, NY Welker McKee Cleveland, OH

Virginia Dickinson North Tonawanda, NY Tim and Nicole Kulikowski

Clay, NY

Bill and Marie Amato North Syracuse, NY Jonnel Company Manlius, NY Stanley and Florence Lachut

North Tonawanda, NY Brian and Marianne Meigs

Cicero, NY Loren W. Pratt Cicero, NY Michael Kuznia and Christie Knapp Syracuse, NY Wayne and Janice Tylec

N. Tonawanda, NY Quermback Electric Inc. Buffalo, NY

Eugene and Gertrude Musial Tonawanda, NY

Mrs. Susan M. Lachut (continued)

Dr. and Mrs. Paul and Meal and Deborah Dickinson Beverley Reeves Medina. OH Scottsville, NY William and Bruce Hellman Kathleen Trotman Rochester, NY Hamnton NH Gordon and Jeanne E. Dickinson Susan Dickinson North Tonawanda, NY Hamburg, NY

A memorial fund has been established in the name of

Mr. William R. Laws

Donations have been made in Mr. Laws' memory by:

John and Dorcia Holtz R.E. Bickham Coleman, TX Alpine, TX

Verizon Foundation

Andover, MA

A memorial fund has been established in the name of Mr. Richard H. Lerner

Donations have been made in Mr. Lerner's memory by:

Lila W. Letchinger Milada Benca Willow Brook, IL Chicago, IL Norman R. Hane Susan Agate and Michael Slutsky Oak Park, IL Fvanston II Patricia A. Buck

Richard and Anne Chalecki Chicago, II Evanston, IL Marcia Horwich

Bette Slutsky Northbrook, IL Evanston, IL Donald H. Sanborn

Geneva, IL Steven and Corrine Brock Wheaton, IL Frank Lloyd Wright Preservation Trust William and

Catherine Blankenship Oak Park II Wheaton, II. Marti Mackin Evanston, IL Kay McSpadden Chicago, IL

A memorial fund has been established in the name of Mr. Gene E. Long

Donations have been made in Mr. Long's memory by:

Bank of Lee's Summit 3W Location Lee's Summit. Missouri Pat Brotherton Independence, MO Ron, Mary and Ann Williams Oak Grove, MO Randy Williams Blue Springs, MO Clifton Garrett Newburgh, IN

Virginia L. Kupersmith Lenexa, KS Frankie and Janis Cowick Independence MO

Clifford and Eleanor Jones Carrollton MO

Helen Yoeger Burlington, Iowa Skip and Lou Joeger Burlington, lowa Carl and Darlene Cowick Carrollton, MO Gary and Gloria Ellis Hardin MO Deborah Hall

Springfield, MO Barbara Lungren Raytown, MO

A memorial fund has been established in the name of **Ms. Lorraine Marie Luck**

Donations have been made in Ms. Luck's memory by:

Mary Fitzgerald, Mansfield, MA

A memorial fund has been established in the name of

Mrs. Patricia Daile Connors Lucks

Donations have been made in Mrs. Lucks' memory by:

James Tucker Potomac Hospital Med Staff Alexandria, VA Woodbridge, VA Hamilton Iron Works, Inc. C. and M. Diaz Woodbridge, VA Fairfax Station VA Kamplang Smith Kathy Cook Germantown, MD Unionville, VA Donna Atkins Cynthia Nuckolls Woodbridge, VA Burke, VA Bert and Leigh Dubay Fred Beaman South Deerfield, MA Elizabeth Yanez

Woodbridge, VA Ron and Sally Henninger Sykesville, MD Tequesta, FL

Robert & Sharon Drennan Charlotte. NC Dumfries. VA

Jackie Estes Morattico VA and Andrea Goss Dale City, VA Patti Lucks Dale City, VA

Dr. and Mrs. Alfred and Judy Kirkwood Sprinafield, VA

Phoenix Steel Erectors. Inc. Haymarket, VA

Robert & Nancy Whitestone

Lakeville, MN

Charlotte, NC Margaret V. Johnson Woodbridge, VA Daile Albanese Gary and Ann Hamilton (Ret.) Ssq and Mrs. Carl Jack and Frances Ferreira

Charlotte, NC Felicia Markham

Arlinaton, TX Richard & Phyllis Lojewski

Plantation, Fl. Dr. Stanley Friedland White Plains, NY

A memorial fund has been established in the name of Mr. Arthur B. Markowitz

Donations have been made in Mr. Markowitz' memory by:

Maggie Cunningham and Robert and Diane Goebes Sarah Stephens Arlington, VA Takoma Park, MD Martha A. Hooker Esther Katzman and Rockville MD Mary Spring Jack and Gail Rosen Silver Springs, MD Boynton Beach, FL Susan Dickerson Mary Liepold Bethesda, MD Silver Spring, MD Rebekah Kaufman Pete and Betty Petersen Baltimore, MD Silver Spring MD

Bertl R. Esenstad Steven and Yelena Luckert Kinder Transport Assn. Silver Spring, MD Silver Springs, MD Major Gen Eugene A. Lupia J. and F. Cirillo

Fairfax Station, VA Fred and Barbara Cohen Rhinebeck, NY

The Super Family Frederick, MD Nova D. Little Takoma Park, MD Jim, Mary and Norah Bird

Orono, ME Dr. Fe Adolfo Rethesda MD

A memorial fund has been established in the name of Dr. Warren William Marguardt

Donations have been made in Dr. Marquardt's memory by:

Denise Marguardt and Hutta Marquardt Hayward, WI

Reston, VA

Tanner Wray

Arts Library

Silver Spring, MD

College Park, MD

Frederick, MD

Paul and Andrea Kane

John and Mitzi Kellev

Silver Spring, MD

Michelle Smith Performing

David and Daidre Bartz Havward, WI

A memorial fund has been established in the name of Mr. Floyd Mattern, Sr.

Donations have been made in Mr. Mattern's memory by:

The Boeing Company
Seattle, WA
Spokane, WA
Boeing Team
Edmonds, WA
Sibylla G. Plantz
Andover, KS
Lorraine Toly
Seattle, WA
Seattle, WA
Sibylla G. Plantz

Kerry J. Kuhlman and Harry S. Kuhlman *Bloomfield, CT*

Christian Women's Fellowship

Bunker Hill, IL

New York, NY

A memorial fund has been established in the name of Ms. Elaine Mayrosh

Donations have been made in Ms. Mayrosh's memory by:

E. Arlene Hammerstone
Easton, PA

Betty Cavanaugh
Phillipsburg, NJ

George Dusichka
Trenton, NJ

Bristol Myer Scribb
Skillman, NJ

Walt and Shirley Kampka
Fort Lauderdale, FL
Gearge Dusichka
Jeannette A. Lucey
Easton, PA

A memorial fund has been established in the name of Mr. William E. McCann

Bruce, "Skeet", Mark Boren

Donations have been made in Mr. McCann's memory by:

First Christian Church Neho II Pittsfield, II Bill and Mona Boren Jack, Kim, Tyler & Quincy. IL Alexis Burns Bruce and Juanita Boren Benld, IL Nebo, IL Ron and Donna Laux Jennifer L. Boren-Miller Pearl, II and Ramona L. Boren Marcia Haun Quincy, IL Bethalto. IL Jeffrey and Becky Johnson Michael and Julia Boren Bunker Hill, IL Pittsfield, IL Jenna and Travis Miller Del and Ruth Brooks Carol Zukilkeh Alton, II Don and Liz Jim and Marcia Stolt Bill and Jo Ann Walker Minonk, II Gale and Janet Boren Ed and Gayle Weichbrodt Ron Orloski & Family

A memorial fund has been established in the name of Ms. Katherine McKeon

Donations have been made in Ms. McKeon's memory by: Arthur and Maida Rosengarten, *Princeton Junction, NJ*

A memorial fund has been established in the name of Mr. Michael Milito

Donations have been made in Mr. Milito's memory by:

Tzell Taylor Made Travel Provi Ramirez Hewlett, NY New York NY Joseph and Naomi Elsner Ralph and Josephine Milito Plainview. NY Floral Park, NY Joseph and Theresa Manfre Kevin and Eileen & Family Oyster Bay, NY Point Lookout, NY Paul and Mindy Wolfle Jerry and Patricia Ennis Long Beach, NY Spring Hill, FL Patricia Kennedy Mark and Janet Levy Freeport, NY Westbury, NY Bo Sin Wong,

A memorial fund has been established in the name of Mr. Lee Miller

Donations have been made in Mr. Miller's memory by:

Mona Kurnit, New York, NY

A memorial fund has been established in the name of Mr. Michael Miller

Donations have been made in Mr. Miller's memory by:

Watkins M. Abbitt, Jr., Appomattox, VA

A memorial fund has been established in the name of Mrs. Ruth Mohr

Donations have been made in Mrs. Mohr's memory by:

Daniel and Beth Sachau Ellen Schultz

Madison Lake, MN Hudson, WI

A memorial fund has been established in the name of Ms. Maria del Carmen Castillo Moya

Donations have been made in Ms. Moya's memory by:

Maritza Penzo de Achecar, Dominican Republic

A memorial fund has been established in the name of Ms. Lycyle Muir

Donations have been made in Ms. Muir's memory by:

Song and Jill Yoon, Plano, TX

A memorial fund has been established in the name of Mr. Michael T. Noble

Donations have been made in Mr. Noble's memory by:

Alison E. Estey
Chelmsford, MA
Andrew & Marilyn Lindquist
Farmington, CT
Anthony & Debra Palermino
Newington, CT
Frank & Susan Cummiskey

Old Lyme, CT

A memorial fund has been established in the name of Mr. John S. (Jack) Nuss

Donations have been made in Mr. Nuss' memory by:

Joseph Lareau, Homosassa, FL

A memorial fund has been established in the name of Mrs. Arlene O'Donnell

Donations have been made in Mrs. O'Donnell's memory by:

James J. O'Donnell, III, Ocean City, NJ

A memorial fund has been established in the name of Mr. Edward Doyle Odum

Donations have been made in Mr. Odum's memory by:

Linda Odum, Bartlesville, OK

A memorial fund has been established in the name of Mr. Harvey Pearlman

Donations have been made in Mr. Pearlman's memory by:

Kenneth and Cynthia Eckstein, Bridgewater, CT

A memorial fund has been established in the name of Mrs. Shirley Peterfreund

Donations have been made in Mrs. Peterfreund's memory by:

Hilda Margiotta William & E. Joyce Jackson Freehold, NJ Portland, OR

A memorial fund has been established in the name of Mr. Frank Pickering

Donations have been made in Mr. Pickering's memory by:

K. Ann DeGraff Stettler, AB, Canada Orest and Jennifer Holubetz Stettler, AB, Canada Allan G. Leinweber Stettler AB Canada Kimy and Bob Poapst Stettler, AB, Canada Darrell Trenholm Stettler, AB, Canada Howard and Rose Fenske Stettler, AB, Canada Rodger and Mary Thomas Stettler, AB, Canada John and Rose Grant Stettler, AB, Canada Heartland Good Sams Stettler, AB, Canada Henry and Mary Eliuk Stettler, AB, Canada Carol Stewart Stettler, AB, Canada Bill and Debbie Hegberg

Stettler, AB, Canada
Markus & Donna Stadelmann
Stettler, AB, Canada
Greg and Karen Hayden
Stettler, AB, Canada
Doug & Georgianna McDavid

Stettler, AB, Canada
Colleen Cregan
Stettler, AB, Canada
Gordon and Marilyn Keibel
Stettler, AB, Canada

Stettler, AB, Canada Max and Lorraine Potter Stettler, AB, Canada Christopher Slifka

Stettler, AB, Canada Kenneth & Helen Horsman Saskatoon, Saskatchewan, Canada Kenneth & Marjorie Hutchinson Fort Qu'Appelle, Saskatchewan, Canada Will and Maxine Rehman, Dianne Ransom& Lome Proctor

Stettler, AB, Canada Stettler Middle School Staff Stettler, AB, Canada 10DE Frontenac Chapter Stettler, AB, Canada

Bob & Rosemarie Holowenko Stettler, AB, Canada Zeke, Carey, Mackenzie & Patrick Ryan Stettler, AB, Canada Jim and Norma Leslie

Jim and Norma Leslie Stettler, AB, Canada Neil and Sara Humphreys Stettler, AB, Canada

Cliff Salvador
Stettler, AB, Canada
Greg Hutchinson
Sask, Canada
Diane Trenholm
Stettler, AB, Canada
Don and Fern Lindstrom
Stettler, AB, Canada
S F H Charity
Stettler, AB, Canada

Penelope Tash Stettler, AB, Canada Lyle and Noreen Pierson Gold River, CA

Gold River, CA

David and Karen Bromley
Stettler, AB, Canada

Robert and K. Willis
Stettler, AB, Canada

Canalta Real Estate
Services Ltd., AB, Canada
Myrtle Elizabeth Horne
Stettler, AB, Canada

A memorial fund has been established in the name of Ms. Marie Pilate

Donations have been made in Ms. Pilate's memory by:

Angelo and Rose Staikos Christine Cavuto Hazlet, NJ Hazlet, NJ

A memorial fund has been established in the name of Mrs. Leticia C. Robles

Donations have been made in Mrs. Robles's memory by:

Stephen A. Lee Rega Park, NY Eileen Kounios Mahopac, NY Marjan Shafieyan Yardley, PA Erika Mariani Los Angeles, CA Veronica Castellanos Winnetka, CA John Manis

Little Neck, NY

Jennifer A. Robles Camarillo, CA Roderick & Rebecca Davis

Corona, CA
Chong H. Yi
Santa Clara, CA
JoAnna Scandiffio
San Francisco, CA

JoAnna Scandiffio San Francisco, CA Nancy Ruvelson Aliso Viejo, CA Barbara Ulanday Juan Los Angeles, CA

A memorial fund has been established in the name of Mr. Jackson L. Rudell

Donations have been made in Mr. Rudell's memory by:

Elizabeth A. Marx, Seattle, WA

A memorial fund has been established in the name of Mr. David Russin

Donations have been made in Mr. Russin's memory by:

Robert P. Rutter, Cleveland, OH

A memorial fund has been established in the name of Ms. Naomi Sapp

A memorial fund has been established in the name of

Mr. Albert J. Sattler, Jr.

Donations have been made in Mr. Sattler's memory by:

Arlene Steinkerchner

Dr. and Mrs. Kenneth Foltz

Blackstone Valley Mothers

Mr. & Mrs. Ralph Eckenberg

Wadsworth, OH

Columbus, OH

of Twins Club Inc.

Woonsocket, RI

Crvstal Falls. MI

Donations have been made in Ms. Sapp's memory by:

Joe and Pat Fehn Dublin, OH Carol Rittenhouse Dansville, NY

John and Betty Zangerle Dansville, NY

Timothy & Patricia Horvath Barberton, OH

Thomas & Mathmlda Matulin Cuyahoga Falls, OH

Darrell and Roseann Pack

Raymond & Barbara Shotter

Putnam County Marine

Mahonac, NY

Seaford NY

Hans Keller

Peekskill, NY

Corps League

Mahopac, NY

A memorial fund has been established in the name of Dr. William (Bill) Sleigh

Donations have been made in Dr. Sleigh's memory by:

Carl and Linda Boast, Moneta, VA

A memorial fund has been established in the name of Ms. Joyce Kaus Smith

Donations have been made in Ms. Smith's memory by:

John Rogalsky and Sharon Itzenhuiser Racine, WI Ron and Jeannine Woods Franksville, WI Sandy Freres Kenosha, WI Leslie F. Stickels Wheaton, IL

Helen Baranoski and

Bristol Myers Squibb Co.

Jerry and Bobbie D'Angelo

New Brunswick, NJ

Princeton Junction, NJ

Dr. and Mrs. Harry and

Richard and Melinda Levin

Peter Lendoch

Middlesex N.I

West Nyack, NY

Marian Levin

Lake Worth, FL

Columbia, MD

Mirielle Shabe

Clarksville, MD

Columbia, MD

Marcy Gitt

Phoenix, AZ

Susan Wagner

Audubon, NJ

Springfield, NJ

Lebanon, NJ

Margaret G. Richlin

The Monday, Wednesday

The Physicians Center, LLC

Fazio, Mannuzza, Roche,

Maurice and Jean Reilley

Tankel, Lapilusa, LLC

and Friday Class plus

Jean Tom

Piscataway, NJ

A memorial fund has been established in the name of Mr. Johnny Stroud

Donations have been made in Mr. Stroud's memory by:

Carol Franta, Ray Shaw and Ann S. Evans, Baytown, TX

A memorial fund has been established in the name of Mr. William J. Targett

Donations have been made in Mr. Targett's memory by:

W. K. and Lorna C. Howenstein Fund, Detroit, MI

A memorial fund has been established in the name of Mr. John P. Tedesco

Donations have been made in Mr. Tedesco's memory by:

Minnie Tedesco *Lakewood, NJ* Anthony Tedesco *Middlesex, NJ* Richard and Melinda Levin *West Nyack, NY*

Charlotte, NC

Lakewood, NJ

Rose Andriani

Lakewood, NJ

Joan Cuozzo

Lakewood, NJ

Anne Gallagher

Lakewood, NJ

Jennie Rasulo

Lakewood, NJ

Lakewood, NJ

Susan Domagalski

South Plainfield, NJ

Mary E. Dellaperute

South Plainfield, NJ

William & Patricia Butrico

Albert and Eleanor Ginter

Lillian Tibus

Nathan and

Clinton, NJ

Whiting, NJ

Clayton and Ruth Beyer

Jacob & Karen Offenbacher

Cortlandt Manor, NY

Eric and Vicki Christensen

Vorldeum Mate. NY

Elliott & Antoinette Bowyer

Yorktown Hgts., NY Frank & Nancy Offenbacher Douglasville, GA

Frank, Kathy Gray & Family

Cortlandt Manor, NY

Jane S. Sattler

Longboat Kev. FL

A memorial fund has been established in the name of Mr. Robert C. Schenck, Sr.

Donations have been made in Mr. Schenck's memory by:

Helen Schenck, Bound Brook, NJ

A memorial fund has been established in the name of Mr. Robert Sebor

Donations have been made in Mr. Sebor's memory by:

Staff at Lawrence Middle School, Lawrence, NY

A memorial fund has been established in the name of Mrs. Helen S. Sherk

Donations have been made in Mrs. Sherk's memory by:

Mary Lou Iserson, Tucson, AZ

A memorial fund has been established in the name of Mr. James H. Sims

Donations have been made in Mr. Sims' memory by:

James and Marilyn Walz
Lake Oswego, OR

Verda Lee Fisher
Bellaire, TX

Carole Spenser
Altoona, WI

Howard Prince
Eau Claire, WI
David and Sue Gordon
Altoona, WI

Mrs. J. Roger Caudill
Morehead, KY

A memorial fund has been established in the name of Mr. Albert "Turk" Torok

Donations have been made in Mr. Torok's memory by:

Debra L. Carberry, D.M.D. *Monroeville, PA*

Art and Helen Divers Gerry McC North Versailles, PA Wilmingtor Patricia A. McKeown Michael an

Clairton, PA
John and Verta Hudak

John and Verta Hudak Bellingham, WA Michael & Kathryn Thornell Millbrook, AL

Millbrook, AL
Gerry McCartha
Wilmington, NC
Michael and Joyce Hudak

Pittsburgh, PA

A memorial fund has been established in the name of Mr. James F. Tonkinson, III

Donations have been made in Mr. Tonkinson's memory by:

Marci, Kerry & Brianna Savrin Warminster, PA
R. E. and Eileen Tonkinson Ormond Beach, FL
Robert and Lynn Strenger

Robert and Lynn Strenger Schwenksville, PA Joseph and Leigh Ogborn Philadelphia, PA Nancylee Hart

Ridley Park, PA

Robert Tonkinson Mahomet, IL Ronald and Grace Hartman

Ronald and Grace Hartm Kintnersville, PA Michael Koniers Warminster, PA Steven O'Mara and Jacqueline Dadario Villas, NJ

A memorial fund has been established in the name of Mrs. Sara Joyce Trachtenberg

Donations have been made in Mrs. Trachtenberg's memory by:

Steven Trachtenberg, Huntingston Station, NY

A memorial fund has been established in the name of Mr. Walter Turchen

Donations have been made in Mr. Turchen's memory by:

San Francisco Veteran Police Officers Assn., Inc. San Francisco, CA Dave and Pat Mayer Burlingame, CA Sol and Jean Weiner

Sol and Jean Weiner San Bruno, CA David and Ginger Wayne Tampa, FL

Maureen Leventon Rohnert Park, GA Ken, Carol Laurie, Lisa and Viv Quadros Granite Bay, CA The De Goff Family Berkeley, CA JoAn Blackstone Little River, CA Ann Barsi Los Altos, CA

A memorial fund has been established in the name of Mr. Richard K. Valentine

Donations have been made in Mr. Valentine's memory by:

Ernest and Elsie Helmke Great Barrington, MA
Rita O'Loughlin Manchester, NJ
Mr. and Mrs. Keith Ridings North Caldwell, NJ
Frank Schwab, Jr. and Staff at Anderson & Schwab Inc. New York, NY

SAIC
San Diego, CA
Margaret C. Shimer
Manchester, NJ
John and Sherri Lange
Midland Park, NJ
Chris Sciglitano
Ridgefield, NJ

Andrew Pedersen

Rumson, NJ

A memorial fund has been established in the name of

Mr. Richard Valicenti
Donations have been made in Mr. Valicenti's memory by:

Jed and Peg Deegan Joan Valicenti Brewster, MA Orleans, MA

A memorial fund has been established in the name of Mr. John D. Tillman

Donations have been made in Mr. Tillman's memory by:

Don and Carolyn Herndon Greenville, AL B. T. and Ann Tillman

Vestavia Hills, AL

Michael & Kathryn Thornell Millbrook, AL Gerry McCartha Wilmington, NC

A memorial fund has been established in the name of

Mr. Don VanRite

Donations have been made in Mr. VanRite's memory by:

Ronda Knutson Gwen Wold
Osceola, WI Amery, WI
Michael Karuschak, Jr. Frances Conrad
Amery, WI Amery, WI

A memorial fund has been established in the name of Mr. Clifford D. Victorine

Donations have been made in Mr. Victorine's memory by:

LISMA Class of 1958 Gen. & Mrs. Richard Beyea Alexandria, VA Alexandria, VA Bob and Audeen Wagner Leroy and Elvine Victorine Hilo, Hawaii Vernonia, OR Ronald and Sue Turner Dick Oberg Manchester, GA Everett, WA Colonel and Ada Scofield Mrs. John Devens Lakewood, WA

A memorial fund has been established in the name of Mr. Karl Wagner

Donations have been made in Mr. Wagner's memory by:

Richard and Audrey Daniels
Voorhees, NJ
Michael J. Baraldi
Voorhees, NJ
Marie K. Wagner
Sewell, NJ
Ted and Jackie Kurowski
Tabernacle, NV

Christopher D. Wagner, Alicia L. Daniels, MD *Medford, NJ*

Lone Tree, CO.

A memorial fund has been established in the name of Mr. Irving Wand

Donations have been made in Mr. Wand's memory by:

Ruth Lublin Richard and Marlene

Bryn Mawr, PA Goldman, San Jose, CA

A memorial fund has been established in the name of Ms. Peggy Ward

Donations have been made in Ms. Ward's memory by:

Ruth Lublin, Bryn Mawr, PA

A memorial fund has been established in the name of Mr. Daniel Wesierski

Donations have been made in Mr. Wesierski's memory by:

Evelyn Cochran Minnie Gaskill Manhattan Beach, CA Brownsville, TX

A memorial fund has been established in the name of Mr. Ray Williams

Donations have been made in Mr. Williams' memory by:

Paul and Ollene Nicolia
Presque Isle, MI
Alfred and Marquerite
Morrone, Clawson, MI
Eugene & Roberta Pourcho
Bloomfield Hills, MI
Margaret A. Goodlin
Mount Pleasant, PA

Paul and Joan Barth Troy, MI

Artemus & Mary Ann Pappas Clarkston, MI

George and Shirley Carley Macomb Twp, MI Ross and Ann Strevel Mt Clemens, MI

Mt Clemens, MI
Boutique To You, LLC
Orion Township, MI
Ivan and Zoe Johnson

Troy, MI
David, Sally and Scott Leak
Suttons Bay, MI

Joyce Shell Utica, MI

Mr. Ray Williams (continued)

Sarietta Waters Waterford, MI Richard & Kathleen Williams

Eastport, MI
Reginald and Ann Bird

Eastport, MI

Dave and Pam Feidner

Rochester, MI
Pat and Karen Lyons
Clarkston, MI

Mike and Becky Stange Lapeer, MI

Dr. and Mrs. Oscar and Elinor Link Bloomfield Hills, MI

Maury and Pat Potter Royal Oak, MI The McCrindle Family

Rochester, MI Harvey and Ruth Berry Indian River, MI

Ed and Donna Bayich Pleasant Hills, LA Jim and Fran Wood

Sterling Heights, MI Fred and Shirleen Kurz Clarkston, MI

Dee Scherer Clinton Township, MI James and Christina Anglin

Clinton Township, MI
Thomas & Jennifer Beagan

Gary and Janice Allegrina Utica, MI

Delmont, PA

Martha Johnston Clarkston, MI

Bernard and Donna Cox *Macomb, MI*

Gilbert and Phyllis Knight Utica. MI

James & Sandra Grashaw

Troy, MI
Beverly J. Crenshaw

Grand Haven, MI
Earl and Doris Rhodes
Sterling Heights, MI

R. N. and Joyce Baughn Rochester Hills, MI

Kenneth & Maryann Kessler Roseville, MI

Nancy B. Vincent Auburn Hills, MI Donis and Janet Harris *Macomb, MI*

James and Nancy White Sterling Heights, MI Betty Lombardi Clinton Two, MI

Terry and Judith Pritchett Washington Township, MI Elmer and Pamela Palmer Sterling Heights, MI

Ronald and Kathleen Miller Wixom, MI

Jeffrey and Katherine Plank Shelby Township, MI

Lawrence & Cynthia Davis Grayling, MI

Matthew & Cheryl Gonzalez Alamogordo, NM George and Mary Jane Schuster Cheboygan, MI Anne Melnyk

aiu

BC, Canada

(Allegheny Intermediate Unit) Homestead, PA

Marnie Marlowe Mc Keesport, PA Marcy Tischuk Pittsburgh, PA

Mindy Sanjana

Pittsburgh, PA
Dennis and Jen Chambers
Washington Twp., MI

Raymond & Martha Smith Shelby Township, MI

Linda Koehne Syracuse, NY

John and Roberta McGrath Romeo, MI

Patricia Deneau Clinton Twp., MI

The Allegheny Intermediate Unit Education Association (AIUEA)

Pittsburgh, PA
Dr. Joseph Petrella
Jeannette, PA

Nancy Scholar Monroeville, PA

James and Judith Tisdale Sammamish, WA

A memorial fund has been established in the name of Ms. Mary Jo Woodward

Donations have been made in Ms. Woodward's memory by:

Eva Hogberg Holland, MI Marian R. Vandebunte Holland, MI

Gene M. Schadler Holland, MI

Dan and Marcia Jasperse Hudsonville, MI Lois M. Huizenga Holland, MI Roberta Sorensen Holland, MI

American Retirement Corp. Brentwood, TN

Michael Milito Research Fund

A memorial fund has been established by the MDS Foundation in the name of Michael Milito. The Milito family made a decision to honor their loved one by establishing this fund to be used for research.

Donations have been made by:

Ralph and Josephine Milito Floral Park, NY

Kevin & Eileen Heneghan & Family *Point Lookout, NY*

Tzell Taylor Made Travel
Hewlett. NY

Joseph and Naomi Elsner

Plainview, NY

Joseph and Theresa Manfre

Oyster Bay, NY

Paul and Mindy Wolfle

Long Beach, NY

Patricia Kennedy *Freeport, NY*

Bo Sin Wong

New York, NY
Provi Ramirez

New York, NY

Ralph and Josephine Milito Floral Park. NY

Jerry and Patricia Ennis Spring Hill, FL

Mark and Janet Levy

Westbury, NY

The MDS Foundation is very grateful for the heartfelt support of the family and friends of Michael Milito. Our work as a non-profit organization depends on public funding. If you would like to contribute in this way, or if you have a unique idea of your own, please write to us at P.O. Box 353, Crosswicks, NJ 08515 or call us at 1-800-MDS-0839.

MDS Foundation Information

The Foundation's Board of Directors

John M. Bennett, MD

Professor of Medicine, Emeritus Laboratory Medicine and Pathology University of Rochester Medical Center Rochester, New York, U.S.A

David T. Bowen, MD

Consultant Haematologist The Leeds Teaching Hospitals Leeds General Infirmary Leeds, United Kingdom

Mario Cazzola, MD

Professor of Hematology University of Pavia School of Medicine Head, Department of Hematology IRCCS Policlinico S. Matteo Pavia, Italy

Theo J.M. de Witte, MD, PhD

Professor of Hematology University Medical Center Nijmegen St. Radboud Nijmegen, The Netherlands

Elihu Estey, MD

Professor of Medical Oncology and Chief of the Section of AML at the University of Texas M.D. Anderson Cancer Center Houston, Texas, U.S.A.

Pierre Fenaux, MD

Professor of Hematology Hôpital Avicenne, University Paris 13 Bobigny, France

Peter L. Greenberg, MD

Professor of Medicine/Hematology Stanford University School of Medicine Stanford, California, U.S.A.

Terry Hamblin, DM, FRCP, FRC Path

Professor of Immunohaematology Southampton University Bournemouth, United Kingdom

Eva Hellström-Lindberg, MD, PhD

Associate Professor of Hematology Karolinska Institutet Institution for Medicine Huddinge University Hospital Stockholm, Sweden

Kathy Heptinstall, BSN, RN

Operating Director
The MDS Foundation, Inc.

Alan F. List, MD

Professor of Medicine
University of South Florida
Chief, Hematologic
Malignancies Division
H. Lee Moffitt Cancer Center
and Research Institute
Tampa, Florida, U.S.A.

Ghulam J. Mufti, MD

Professor of Haemato-Oncology University of London King's College Hospital London, United Kingdom

Charlotte M. Niemeyer, MD

Professor of Pediatrics University Children's Hospital Freiburg, Germany

Stephen D. Nimer, MD

Head, Division of Hematologic Oncology Memorial Sloan-Kettering Cancer Center New York, New York, U.S.A.

Robert J. Weinberg, Esq.

Pepper Hamilton LLP Philadelphia, Pennsylvania, U.S.A.

Emeritus Member Franz Schmalzl, MD

Innsbruck, Austria

Membership Information

The MDS Foundation would like to have you as a member. Membership is US\$40 a year for physicians and other professionals. Patients, their families, and others interested in MDS may join at the reduced rate of \$25.

Membership benefits include quarterly issues of the MDS News, a special subscription rate of \$116 for Leukemia Research (a substantial discount from the current institutional subscription rate of \$2,373), and the worldwide Centers of Excellence patient referral service.

If you would like additional information, please contact us at:

The MDS Foundation 36 Front Street, P.O. Box 353 Crosswicks, NJ 08515

Phone: 800-MDS-0839, Fax: 609-298-0590 Outside the US only: 609-298-1035

About the Foundation

The Myelodysplastic Syndromes Foundation was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS.

Until the Foundation was set up, no formal working group had been devoted to MDS. During the past decade we have conducted nine international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, France, Japan, and Italy. The Tenth International Symposium is being held May 6–10, 2009 in Patras, Greece.

A major Foundation effort is our international information network. This network provides patients with referrals to our Centers of Excellence, entry into available clinical trials, sharing of new research and treatment options between physicians and researchers, and extension of educational and emotional support to physicians, nurses, patients, caregivers, and others working with MDS patients.

In response to the needs expressed by patients, families, and physicians, we have established Patient Advocacy Groups, research funding, and physician education.

The MDS Foundation is a publicly supported organization, exempt from federal income tax under section 501(C)(3) of the IRS code.

Our Website

The MDS Foundation webpage is for healthcare professionals, patients, and other interested people. The Professional Forum and the Patient Forum are integral parts of our website.

The website is constantly being updated to better serve the needs of our patients, their families, and the physicians who treat them. Please visit us at www.mds-foundation.org.